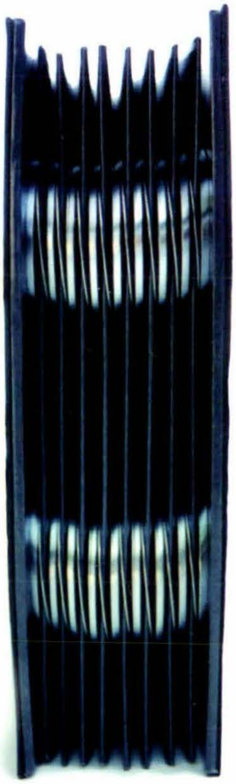
A user-centred approach to the design and evaluation of a Patient Information Manual



2000

Glenna Duthie

A user-centred approach to the design and evaluation of a Patient Information Manual to aid adolescent patients' health care and healing

This Thesis Supports
a Practice-Based Research Project
for the fulfilment of a
Master of Design Degree
College of Design, Fine Arts and Music
Massey University, Wellington

1 April 2000
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abstract

In our current technological environment, designers are encouraged to identify, define and meet people's needs by undertaking user-centred research, working with experts in other fields, and by becoming 'producers' of their own designs. In this thesis the designer has taken on these roles to address information and communications issues in the health sector.

This research study seeks to improve the heath care and healing processes of adolescent patients by a practical application of visual communications design. The research takes a holistic approach by considering the social, therapeutic, and creative needs of adolescent patients as they relate to the use of typography, illustration, colour, and packaging design. Information design, communications theory, and play therapy inform the approach taken.

Educational and recreational resources designed for adolescent patients are virtually non-existent in New Zealand hospitals. Instead, most of the information relating to the hospital services and the patients' conditions and treatment is communicated verbally by the hospital staff. This can disadvantage adolescent patients who tend to dislike communicating with people in positions of authority. Because adolescents have been found to be highly visually literate, adolescent patients needs can best be addressed by innovative visual communications design solutions.

The designer used both quantitative and qualitative research methods to investigate the complexity of adolescent patients' needs. Because the questionnaire survey of adolescent patients and the interviews with health professionals were conducted in hospitals in Auckland and Wellington, the designer was faced with the daunting task of getting approval from three separate ethics committees and from the related clinical boards before the research could be conducted. However the many administrators and hospital staff approached willingly gave their time to help ensure that the resulting design would be both appropriate and relevant.

With the research findings, the designer succeeded in developing a comprehensive communications system involving informative pamphlets, games, and activities that addressed the needs identified in the research. The designer also developed a packaging system that contained and displayed its contents in an appealing and innovative way. This thesis must be read in conjunction with the practice-based component of the research study described in chapter 5 (page 65-91).

Ongoing evaluations with health professionals and adolescent patients have suggested modifications to improve the design and have also confirmed that the resulting Patient Information Manual (PIM) is both highly appropriate and extremely helpful in addressing adolescent patients' needs. There has already been widespread interest and offers of support to help ensure that this design is available for use in public hospitals in New Zealand.

acknowledgements

This project would have been impossible to pursue without the knowledge and encouragement of many people. This is in grateful acknowledgment:

to my supervisor, Associate Professor Leong Yap (Massey University) whose knowledge of design theory and practice, patience, and good humour overcame the incomprehensible, unsolvable, and impossible,

and to Jürgen Waibel (Massey University) for repeatedly sending me back to the drawing board buzzing with new ideas and humbled by design history.

to the adolescent patients whose thoughtful responses while still on their hospital beds gave meaning to this project.

to the health professionals whose thoughtful comments and suggestions during the interviews helped to shape the final design: in particular to Peter Watson, Carol Bolton and Sandra Murphy for sharing their knowledge and time.

to the many administrators and health professionals who generously gave their time during the process of contacting health professionals and in gaining ethical approval: particularly to Associate Professor Carl Burgess, Heather Elias, Vicky Noble, Marjian Hawley, Jo Griffin, Sharon Cole, and Candy Pettus.

to those who kept a friendly eye on my progress: to Soohyang Song, Shivaun Hogan, and Lian Hathaway; and to Nita Hill, Keri Hubbard and Jane Ewing for boundless support and for their personal dedication to improving the quality of life of hospitalised patients.

and finally to my family: to Struan Ashby and Erica for numerous photo shoots, for practical, technical and aesthetic advice and support; to Val and Birnie for proof reading, many enjoyable hours of animated discussion, and for their unfailing encouragement, and to Master for company, fresh air, and sunshine.

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introduction

1

Research in the field of adolescent patient's management over the last ten to fifteen years has indicated that the New Zealand public hospital system is not set up to adequately cater for adolescent patients' needs and expectations. New Zealands' small population has mitigated against the creation of adolescent wards and so adolescents are generally treated in children's or adult's wards, and by staff members who are not trained to respond to their developmental needs. In this situation adolescents are more likely to feel bored and alienated.

A Department of Health Report that explored the needs of these patients suggested that adolescents would benefit from the provision of 'recreational and educational support in hospital.[1] These suggestions are echoed in the survey findings of Cledon et al which recommended that activities such as games and books be made available.[2] Recreational and educational support is currently available through Children's Teachers and Play Specialists in hospitals, but nearly all of the existing resources are designed for younger children and, to date, no provision has been made for adolescents as young as thirteen and fourteen who are sometimes placed on adult wards.[3]

Research indicates that the developmental issues of identity and independence tend to make adolescent patients' experience in hospital particularly problematic.[4] Adolescent patients complain of boredom and are often unwilling or afraid to ask questions.[5] This has resulted in adolescents earning a reputation for being difficult to care for as a proportion of them are 'uncommunicative', 'withdrawn' and 'non-compliant with treatment'.[6] It would seem that these undesirable adolescent behaviours could be modified, and staff-patient communications could be improved, if adolescent patients felt that their needs were being addressed in hospital.

Adolescent patient needs can best be addressed by developing a resource that encourages adolescents to take an active interest in their treatment and recovery, facilitates staff-patient communications, and provides the patients with a means to relieve their boredom. In developing the Patient Information Manual (PIM), the emphasis has been on the design of a visual communication system that is readily accessible and user-friendly, and that contains relevant information, engaging activities, and good communications strategies designed specifically to appeal to this age group.

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[1] O'Regan, K. Adolescent Health: Potential for Action. Wellington: Department of Health, June 1992

[2] Clendon, F. et al. *Is Dunedin Hospital Suited to Adolescent Patients?* A Department of Preventative and Social Medicine Trainee Intern Health Care Evaluation Project. University of Otago, 1986

[3] Children's Teacher Discussions in Wellington Hospital, 15/3/1997

[4] Cain, W. *Theories of Development: Concepts and Applications.* 3rd ed. New Jersey: Simon and Schuster Co, 1992

[5] Maskill, C. *A Health Profile of New Zealand Adolescents.* Wellington: Department of Health, 1991

[6] Shenker, R. *Adolescent Medicine.* Harwood Academic Publishers: Switzerland, 1994

1.1 research aim

To design and evaluate a Patient Information Manual (PIM) that contributes to the health care and healing processes of adolescent patients.

1.2 questions

What are the needs of hospitalised adolescent patients?

How well do existing resources for patients meet adolescent patients needs?

What formats, typography, illustration and colour are popular to an adolescent audience?

What content, forms and colours could be used to aid the patients emotional and physical healing processes?

As well as providing adolescent patients and hospital staff with a well designed communications system, this thesis will also demonstrate how a holistic, user-centred research process can inform innovative design solutions to meet the real needs of an institutionalised audience.

1.3 overview

Chapter 1 contains the introduction, research aims and expected outcomes.

Chapter 2 explores literature relating to designers as 'producers', user-centred design, and needs-based design. Followed by a description of adolescent patients, and an indepth analysis of their needs as they relate to communications, information, activities and expression.

Chapter 3 describes the methodologies used to conduct hospital staff interviews and an adolescent patient's survey to confirm and extend the findings of the literature review. This chapter also outlines the process of gaining approval to conduct this research in hospitals.

Chapter 4 contains the findings of the interviews and questionnaire survey, and outlines the design criteria.

Chapter 5 covers the development, design and evaluation of the packaging prototypes, pamphlets and activities (the PIM).

Chapter 6 contains the concluding statements and recommendations.

Chapter 7 the bibliography

Appendix extracts from the staff interviews and the patients' questionnaire

literature review

2

Recent literature on Visual Communications Design, Communications, and Design Research highlights the importance of placing the end-user or intended audience at the centre of the design process. Some of the writings also suggest that designers should be socially responsible and work towards helping people to meet their own needs. To this end, the role of the designer is seen to be more actively involved his/her audience in all stages of a project's development, so that the audiences' views are taken into account in the generation, research, and development of design solutions.

2.1 designer producer

Rapid technological changes in the last twenty years have made some of the traditional roles of visual communications designers redundant, while creating new needs that designers can be well positioned to address.

Historically, designers have often been seen as experts in 'good taste'[1] or 'stylists'[2]. Many designers have taken on the role of 'neutral and obedient servants' by unquestioningly giving form to other people's messages.[3] Currently a much wider section of society has access to formatting and styling capabilities through computerised technologies, such as the internet, word processing, and graphics programs. This means that the demand for designers who 'simply shape content' is waning.[4] [5]

While technology has reduced the need for 'stylists', it has generated an urgent need for visual communicators to help people understand and manage information.[6] The instantaneous global distribution and duplication of information, that is currently being authored by a large cross-section of society, has created an information explosion, with its associated problems of 'information overload' and 'information anxiety'.[7] This is particularly significant in health and medicine where hospitals, support groups, and individuals have generated large volumes of medical advice, information, and misinformation - all of which is available for viewing by the general public through the internet.. As more specialised information becomes available to a wider audience designers are increasingly needed to present information clearly.

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[1] Cossette Claude (1996): *Design As Communication*: discussion thread. [www document] http://www.xs4all.n1~plato/designascom.html [8/10/99]

[2] Roth, Susan. 'The State of Design Research' *Design Issues.* Vol XV No 2 1999

[3] McCoy, Katherine. 'American Graphic Design Expression' *Design Quarterly* No148 p4-22 1990

[4] Hales, David. 'Evaluating Design the Non-Linear Way' *Aiga Journal of Graphic Design* Vol 12 No3 132-36 1994

[5] Swanson Gunnar. 'Is Design Important?' *Aiga Journal of Graphic Design* Vol 13 No1 p4-5 1998

[6] Dervin, Brenda (1995): *Chaos, Order, and Sense-Making: A Proposed Theory for Information Design.* [www document] http://edfu.lis.uiuc.edu/allerton/95/s5/dervin,draft.html [7/10/99]

[7] Shedroff, Nathan (199.): *Information Interaction Design: A Unified Field Theory of Design.* [www document] http://www.nathan.com/thoughts/unified/index.html [8/10/99]

Accessibility to information affects patients in a variety of ways. It has been found that patients are very concerned about conflicts in the information they receive.[8] Having large volumes of information is meaningless unless clear and appropriate information can be accessed, understood, and used.[9]

Research by Grinder has shown that some people learn best by listening (auditory learners), some by seeing (visual), and others by doing (tactile, kinaesthetic).[10] It is important that information is presented using a combination of visual, audio and tactile media so that the information is accessible to a wide audience. Most of the information given out in hospital is auditory, as doctors and nurses give patients verbal explanations and instructions that relate to their test results and treatments.

Pauwels notes that this education process could be enhanced by 'audiovisual and other aids' among which she includes drawings, models, charts, and educational brochures.[11] The inclusion of visual media is seen to be particularly useful in the case of adolescent patients who have grown up with television, video, and playstations and who are purported to be highly visually literate.[12] [13] Therefore, a wider use of visual and tactile media would increase the success rate of staff-patient communication in hospital.

The discipline of design is uniquely suited to playing a central role in this new environment because of its cross-disciplinary nature. As an 'integrative discipline', design has often focused on problems and subjects outside its own.[14] Also, having no academic tradition, designers have had to use and be familiar with the terminology and methods of other disciplines.[15] [16]

Lupton has recognised these changing times as an opportunity for graphic designers to take on a new role of 'producer'. In this role the designer becomes active in generating, interpreting, and critiquing content. Lupton describes this process as infusing 'the act of making with the act of thinking'.[17] Roth also talks of the designer's role as changing to that of a team member, an interpreter of complex systems, a communicator, and a problem solver.[18]

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[8] Dervin, Brenda (1995): *Chaos, Order, and Sense-Making: A Proposed Theory for Information Design.* [www document] http://www.edfu.lis.uiuc.edu/allerton/95/s5/dervin.draft/.html [7/10/99]

[9] John, Robert (1995): *About Info Design.* [www document] http://www.xs4all.n1/~plato/aboutinfodesign.html [8/10/99]

[10] Dryden, Gordon and Dr Jeannette Vos. *The Learning Revolution.* Auckland: The Learning Web 1997

[11] Pauwels, Anne. *Cross-Cultural Communication in the Health Sciences* Australia: Macmillan Education 1995

[12] Haines Recruitment Advertising. *A Presentation on Life as a 90's Teenager.* Wellington August 1997

[13] Haines Recruitment Advertising. *A Presentation on Life as a 90's Teenager.* Wellington August 1997

[14] Stickler, Zoe. 'Elicitation Methods in Experimental Design Research' *Design Issues.* Vol 15, No 2 1999

[15] Roth, Susan. 'The State of Design Research' *Design Issues.* Vol XV No 2 1999

[16] Miller, John Jay (1996): *Design As Communication:* discussion thread. [www document] http://www.xs4all.n1/~plato/designascom.html [8/10/99]

[17] Lupton, Ellen (1997): *The Education of a Graphic Designer: The Designer as Producer.* [www document] http://www.allworth.com/Articles/article20.htm [8/10/99]

[18] Roth, Susan. 'The State of Design Research' *Design Issues.* Vol XV No 2 1999

However, these design theorists also consider it important that designers do not take on the historical role of 'author' and consider themselves as sole creators, but rather that they should work closely with a team of experts in other fields and disciplines.[19] [20]

2.2 user-centered research

Roth also suggests that designers take a more empirical approach to their work by undertaking user-centred research. To date, 'this has been an uncommon practice' in the fields of visual communications and graphic design.[21] Carson describes the lack of accountability in graphic design as a 'freedom' granted to designers because the risk is low when designing cheap and ephemeral products like magazines.[22] However, in the absence of feedback from the end-users, it is very easy for designers to assume that they 'know what is best for everybody'[23] and that their preferences, perceptions and needs are representative of their intended audience.[24] These problems could be avoided with the 'appropriate research and evaluation methods' that are already standard practice in architectural and industrial design.[25]

User-centred design is not simply a matter of including user evaluations in the final stages of design, but instead seeks the user's input from the generation of the initial ideas through to product completion.[26] User-centred design is also more involved than just asking people 'what they want'. Instead, designers need to prepare themselves with the knowledge of likely issues to allow them to ask questions and respond to answers appropriately.[27] Part of this preparation should include learning about the users capabilities, experiences, philosophies, and perceptions so that designers can make informed decisions based on knowledge of the 'complete person' in their environment.[28]

In a health care setting, a patient's ability to understand and act on new information can have a significant impact on a patients' recovery and on their very survival. Inappropriate or confusing communications is known to lead to distrust, misunderstanding, and inappropriate courses of action by patients.[29] Therefore it is important that pamphlets and books should not be in

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[19] Lupton, Ellen. 'The Designer as Producer' *Aiga Journal of Graphic Design* Vol 15 No3 p6-7 1997

[20] Blauvelt, Andrew and Meredith Davies. Building Bridges: a Research Agenda for Education and Practice' *Aiga Journal of Graphic Design* Vol 13 No 1 'p14-17 New York. 1995

[21] Roth, Susan. 'The State of Design Research' *Design Issues.* Vol XV No 2 1999

[22] Carson, David. New York: Rizzoli 1996

[23] Waller, Rob (1995): *Information Design:* discussion thread. [www document] hppt://www.nathan.com/thoguths/unified/index.html [8/10/99]

[24] Glanville, Ranulph. 'Researching Design and Designing Research'. *Design Issues.* Vol XV No 2 pp 80-91 1999

[25] Roth, Susan. 'The State of Design Research' *Design Issues.* Vol XV No 2 1999

[26] Indiana *What is User-Centered Design?* [www document] http://www.indiana.edu/~usable/howto.htm

[27] Scott, Andrew (1996): *Design As Communication:* discussion thread. [www document] http://www.xs4all.n1/~plato/designascom.html [8/10/99]

[28] Osborne, D et al. *Person-Centered Ergonomics: A Brantonian View of Human Factors.* London: Taylor and Fracis Ltd 1993

[29] Pauwels, Anne. *Cross-Cultural Communications in the Health Sciences: Communicating with Migrant Patients.* Melbourne: Macmilian Education 1995

conflict with practitioner's advice.[30] Any information that patients are given must be relevant, informative, accurate, and above all must communicate clearly.

User-centred design is increasingly being recognised as an important component in improving patient education. Stickler notes that 'collaborative, user-focused studies in communication design are currently highly fundable through traditional granting institutions, especially in health and epidemiological areas.'[31]

2.3 satisfying user needs

Archer links the solving of design problems with the identifying of needs. He argues that there can be no solution without a problem, no problem to solve without constraints and no constraint without a pressure or need.[32] Whitely agrees with Archer and adds to Archer's findings by arguing that good design is neither universal nor eternal, but is that which satisfies the needs (material) and desires (emotional) of an individual or group at a particular time in a particular place.[33]

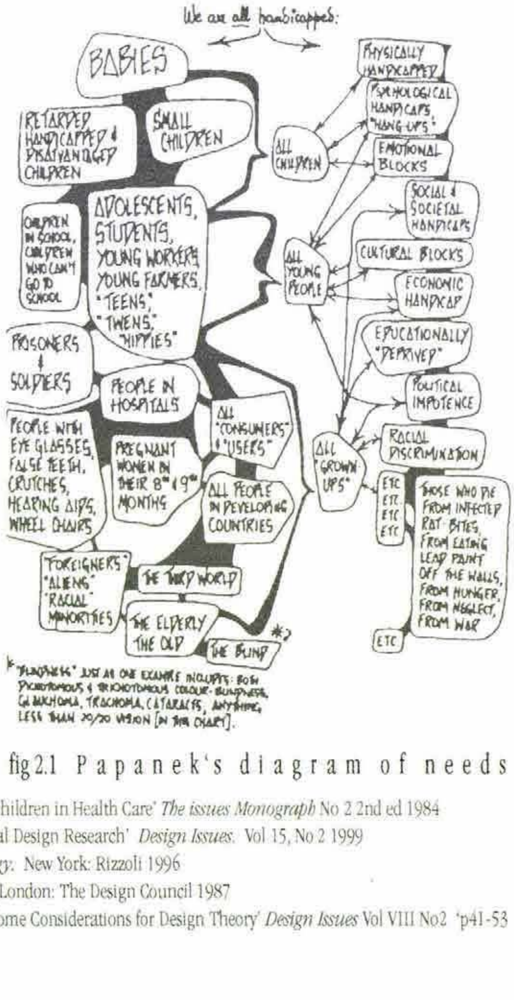

fig 2.1 Papanek's diagram of needs

Papanek encourages designers to be socially responsible by considering people's genuine needs. He maintains that designers should not limit themselves to responding to the desires of an 'average consumer' from the middle and upper class but should also use their skills to help disadvantaged groups like the poor, the sick, the elderly, and the disabled (fig 2.1). He believes that designers should seek to address genuine needs as opposed to people's desires and wants.[34]

Maslow, a psychologist, developed a theory about human needs. He describes people as always being in the

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[30] Lindquist, Patricia et al. 'Psychological abuse of children in Health Care' *The issues Monograph* No 2 2nd ed 1984

[31] Stickler, Zoe. 'Elicitation Methods in Experimental Design Research' *Design Issues.* Vol 15, No 2 1999

[32] Cross, Nigel. *Introduction to Design Methodology.* New York: Rizzoli 1996

[33] Whitely, Nigel. *Pop Design: Modernism to Mod.* London: The Design Council 1987

[34] Fry, Tony. Against an Essential Theory of Need: Some Considerations for Design Theory' *Design Issues* Vol VIII No2 'p41-53 1992

state of wanting something and that they are seldom completely satisfied as they move up their own 'hierarchy of needs' from physical needs through to intellectual and spiritual needs. Under the category of threats to people's basic needs he includes: threats to a person's life; threats to their general integrity; and threats to their basic mastery of the world.[35] All of these threats are faced by adolescent patients in hospital and are of significant concern to the development of the PIM. These issues are further explored in an in-depth investigation into patients' needs in the remainder of this chapter and in chapters four.

Maslow's suggested solutions to these threats include improved knowledge, understanding, and self expression.[36] Both Papanek and Maslow assert that peoples' needs can best be met by a mixture of research (knowledge), education (understanding) and creativity (individual expression) (fig 2.2). Papanek goes on to claim that these activities are all part of the design process (fig 2.3).[37]

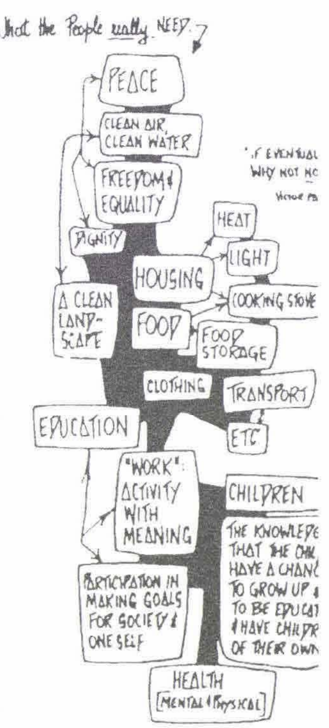

fig 2.2 Papanek's solutions

Designers however, should seek to do more than just meet peoples' needs. Archer defines a good environment, and Papanek defines a good design solution, as one that allows people to meet their own needs and which provides people with real choices.[38] [39] Papanek states that these choices should be real and meaningful, allowing people to participate more fully in their own life decisions, and enabling them to communicate with designers and architects in finding solutions to their own problems - in effect to become their own designers.

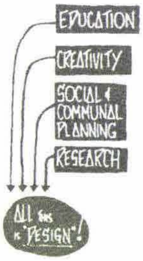

fig 2.3 Papanek's solutions

Therefore in this study the designer takes on the role of producer by identifying, defining and solving real problems with the help of experts in the field. Taking a user-centred approach, the designer has researched the patients' needs in detail to inform the nature, form, and content of a design solution.

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35 Maslow, A. H. *Motivation and Personality.* U.S.A.: Harper & Row Publishers1954

36 Maslow, A. H. ibid. 1954

37 Papanek, Victor. *The Green Imperative: Ecology and Ethics in Design and Architecture* USA: C.S. Graphics 1995

38 Cross, Nigel. *Introduction to Design Methodology.* New York: Rizzoli 1996

39 Papanek, Victor. *Design for the Real World: Human Exology and Social Change.* USA: Thames and Hudson 1984

2.4 adolescent patients

'Adolescent', 'teenager', 'juvenile', 'youth', and 'young person' are overlapping definitions which describe those who are no longer children but not yet adults. The characteristic they all have in common is the transitional nature of their lives. Defining this group by chronological age is problematic because individuals mature at individual rates. Depending on the definition used, young people can be said to take anywhere between weeks and decades in the a state of limbo between being a child and becoming an adult.[40] The World Health Organisation define adolescents as ten to nineteen year olds, youth as fifteen to twenty four year olds and young people as ten to twenty four year olds.[41] The Specialist Youth Health Service chose to use all these terms interchangeably to refer to those between the ages of ten and twenty-four.[42] This PIM study will likewise use these terms interchangeably, but it will focus on the thirteen to twenty year olds; beginning with the biological changes of puberty in the early teens and ending when New Zealanders are legally defined as adults at the age of twenty[43].

Adolescence is often considered to be a pivotal time in a young person's life. While Rousseau considered the process to be a second birth,[44] Erikson linked adolescence with the psychological stage of 'identity formation versus role confusion'.[45] The status, rights, responsibilities, and life styles of adolescents are constantly changing as they develop physically into adults. Many of the issues that adolescents are said to face relate to their increasing independence, emerging sexuality, and developing identity.[46] Historically, these developmental processes became issues when the demand for higher education kept young people institutionally segregated from other ages in schools, and prolonged their dependence on families.[47] Today's teenagers develop in a new environment where many of them seek refuge from their broken families in 'global tribes', form their identity by navigating numerous television channels, and test their independence with designer drugs and heavy drinking at all night 'raves'.[48]

Although the Central Regional Health Authority Report 1995 states that the majority of adolescents are very healthy, it has been estimated that as many as one in ten will be admitted to hospital each year.[49] The main reasons that adolescents are admitted to hospital include asthma, head injuries, motor accidents, suicide, unplanned pregnancy and cancer.[50]

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[40] Kett, Joseph. *The Disapearance of Childhood* 1977

[41] World Health Organisation Report 1980

[42] World Health Organisation Report 1980

[43] Age of Majority Act 1970 cited in Maskill *A Health Profile of New Zealand Adolescents*. Wellinton:Department of Health 1991

[44] Rousseau, J. *Emile*. London 1911

[45] Erikson, Erik. *Identity, Youth and Crisis*. New York: Norton 1968

[46] South Auckland Health, Child Health Serivices *Developmental Support Plan - Adolescents*. Auckland1999

[47] Neil Postman *The Disapearance of Childhood* 1982

[48] Haines Recruitment Advertising. *A Presentation on Life as a 90's Teenager*. Wellington August 1997

[49] Bennett, D. *Growing Pains: What to do When Your Children Turn into Teenagers* Auckland: Hodder & Staughton Ltd 1987

The average length of stay in hospital is just one or two days, but there are various conditions that require longer periods of hospitalisation, like cancer, burns, rheumatic fever, and cystic fibrosis.[51] These long-stay adolescent patients require more educational and recreational support than short-term patients. The PIM will seek primarily to address the needs of these long-stay patients.

2.5 adolescent units

There has been a world-wide movement towards dealing with adolescents as a distinct group with particular health profiles and needs. This movement began in the United States with the establishment of the first adolescent unit in 1951, followed by adolescent medicine being recognised as a speciality in the 1970s. Since then countries as diverse as Finland, the Philippines, Austria, and Israel have all founded adolescent units in their hospitals. Australia also recognised adolescent medicine as a speciality in the 1980s.[52] New Zealand has not taken up this initiative in its treatment of young people.

Although some attempts have been made to set up adolescent units around New Zealand, our small population and the lack of trained staff have made these initiatives impossible to sustain (there is currently only one Medical Specialist in New Zealand who is trained and practicing in adolescent medicine). Adolescent patients are generally treated as children in paediatric wards or as adults in the general wards. Adolescents as young as thirteen and fourteen can find themselves isolated on general adult wards. Their numbers in hospital wards range from around one a week to one or two a year. Hospitalised adolescents in New Zealand are considered to be a 'small niche market'.[53] Despite their comparatively small numbers, the designing of resources to help this group has the potential to be particularly rewarding. It is important that adolescents have the tools to manage their own health care. This will not only work towards optimising their current health care and recovery, but will encourage adolescents to take more responsibility for their health in the long term.[54]

2.6 existing surveys

It is unwise to make assumptions about any groups' problems and needs, or to put forward suggested solutions, without first learning about the groups themselves and how they experience their situation. Adolescent patients and their perceptions of the hospital experience have not been extensively researched in New Zealand. It was possible, however, for the designer to identify

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[50] Central Regional Health Authority *Young Health Your Health* New Zealand 1995

[51] Discussions with Hospital Staff New Zealand 1999

[52] Bennett in Maskill, C. *Health Profile of New Zealand Adolescents.* Wellington: Department of Health 1991

[53] Discussions with hospital staff New Zealand1999

[54] Learmonth, Andrew *Disease Ecology* Oxford: Gasil Blackwell Ltd 1988

some of the potential issues that adolescents face from relating adolescent issues with patients' needs. These issues were further clarified in reference to the following New Zealand surveys:

Haines Survey: *What really goes on in the Teenage Mind?: A presentation on life as a '90s Teenager* - conducted in 1997 courtesy of the Haines Recruitment Agency. In this survey 800 teenagers in Auckland were interviewed about their lifestyles and attitudes to advertising design. The conclusions reached by this survey helped to determine the design approach used.

Morris Survey: *Looking After Yourself: Some Views From 15-19 Year Olds on Health and Illness* - conducted in 1985 by Morris. 60 teenagers in Wellington between the ages of 15 years and 19 years were asked about their views on health in general. 33 of them had been hospitalised, eighteen more than once. This survey provided an insight into adolescents' perceptions of their health in general.

Cledon Survey: *Is Dunedin Hospital Suited to Adolescent Patients?* Conducted in 1986 by Cledon et al. 70 teenagers from Dunedin were surveyed by questionnaire for their opinions on all aspects of being in hospital. The findings from this survey provided answers to questions that covered many aspects of the adolescent patients' experience.

2.7 problems and solutions

The problems that adolescent patients face and potential design solutions to those problems are explored in the remainder of this chapter as outlined:

2.7.1 Patients Surroundings: discusses the need for visual stimulation within sterile hospital environments, relating this to developmental issues of identity. This section also explores the psychological and therapeutic uses of colour.

2.7.2 Staff-Patient Relationships: focuses on problems associated with staff-patient relationships and explores how design can be a catalyst for dialogue in social interaction.

2.7.3 Existing Information: explores how information relating to patients rights, treatment and informed consent could be presented using typography and layout that would engage adolescent patients.

2.7.4 Games and Activities: shows how presenting information in the forms of games and activities can address adolescent patients experience of boredom in hospital by introducing the element of play.

2.7.5 Creative Expression: explains the importance of including creative and expressive activities to address the feelings of isolation and low self-esteem that adolescent often experience.

2.7.1 patients‘ surroundings

As part of the overall holistic approach taken in the development of the PIM, literature on the patients' surroundings was examined. It was found that the hospital environment itself increased adolescents' feelings of alienation, and that this could be detrimental to their healing and recovery.

Studies have shown that some environments are more conducive to recovery than others.[55] An ideal environments meets the patients' needs for privacy, rest, relaxation, and safety, and gives them access to nature and to clean air. An ideal environment also surrounds the patient with familiar sounds, smells, sights, and faces.[56] Within the present configuration of the New Zealand public hospital system patients do not find themselves in healing environments. They are often placed on wards where their private space is reduced to a bedside table within a sterile interior world. The lack of special facilities for teenagers in hospital means that they find themselves in wards designed for people much younger, or much older, than themselves.[57] For adolescents who are sensitive about their privacy and identity, this is a particularly uncomfortable environment.

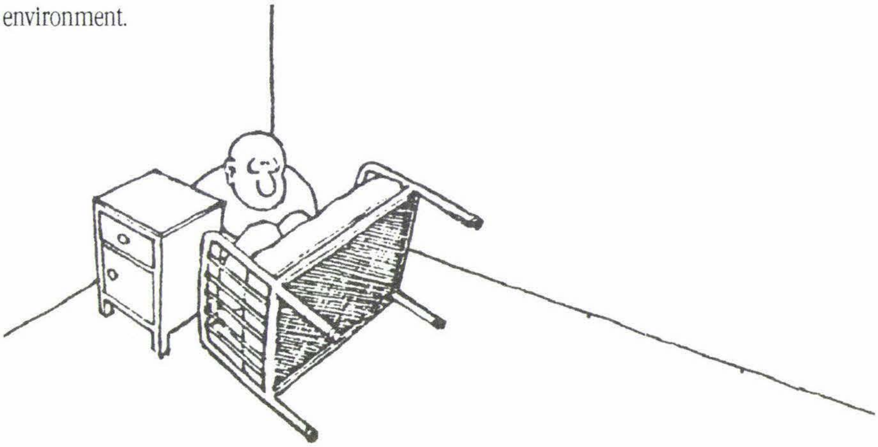

fig 2.4 private space is reduced in hospital

Adolescent concerns about their surroundings have been registered in patient surveys where they have mentioned how they would prefer not to have Mickey Mouse all over the walls,[58] would like to be able to open windows, are affected by the lack of view from some the hospital rooms. They have also commented on the absence of colour in their environment. Some of them also requested more paintings, murals, and plants.[59]

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55 Moyers, Bill. *Healing and The Mind.* London: Harper Collins 1993

56 Smith, Dorothy W. *Survival of Illness: Implications for Nursing.* New York: Springer Publishing 1981

57 Percival, Anne. Traumatic Events in the Lives of Adolescents. *Paediatric Nursing.* Vol 11 No 6 July 1999

58 Robertson, Suzanne. *What Do You Think and Why? A Survey of Princess Margaret Hospital Inpatient Adolescents and Their Parents.* Nov 1997

59 Cledon et al. *Is Dunedin Hospital Suited to Adolescent Patients?* Otago: University of Otago 1986

Even if it were possible to supply adolescents with more visual stimuli in their surroundings, adolescents can prove to be difficult customers to satisfy. As part of the developmental process of identity formation, teenagers are renowned for their extreme and rapidly changeable preferences. The Haines survey found that teenagers do not think of themselves as a generation, but as part of 'global tribes'. As individuals they tend to move through stylistic stages with unprecedented speed, and are derisive of their own tastes/behaviour from their recent past and of those younger than themselves. They have a tendency to be anti-fashion and to be wary of trends; they do not want adults to know where they are 'coming from'.[60] The findings suggested that any attempt by a designer to evoke a 'teenage feel' was likely to be unsuccessful with the majority of teenagers because during this period they prove to be so diverse and changeable in their tastes.

LeShan, a practitioner of holistic medicine, created an effective solution to this problem. He introduced a scheme that allowed patients of all ages to choose images for the walls of their ward rooms from a library of posters and images. While this scheme proved very popular amongst the patients, he encountered resistance from the hospital staff. LeShan observed that patients are often not encouraged to make decisions about their spaces in hospital, and he suggests the reason for this could be that staff in institutions find it easier not to acknowledge patients as people with individual identities.[61]

Teenagers especially value being able to express their identity through their surroundings, be it their bedroom at home or their space in a hospital ward. Purtilos maintains that:

'The length to which he [a teenage boy] goes to maintain his identity become apparent when one walks into his hospital room: the evidence is plastered on the walls, tied to the bedposts, and hanging from the ceiling. In his appearance, manner and language, the teenage patient declares, I'm still in.' Ruth Purtilo 1984[62]

Torrice and Logrippo, who specialise in designing environments for young people, found that the absence of colour, specifically in hospital settings, had a profoundly detrimental effect on the teenagers they worked with. They describe the state hospital setting as 'sterile and devoid of light'. They found that the 12 to 16 year olds changed from being aimless, anxious individuals, to responsive and relaxed people when they were removed from the hospital environment and experienced natural colours in full spectrum light.[63] According to colour theory as it relates to

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[60] Haines Recruitment Advertising. *A Presentation on Life as a 90's Teenager.* Wellington August 1997

[61] Leshan, Lawrence. *The Mechanic and the Gardener: Making the Most of the Holistic Revolution in Medicine.* New York: Holt, Rinehart and Winston. 1982.

[62] Purtilo, Ruth. *Health Professional/Patient Interaction.* Philidelphia: W.B.saunders Co 1984

[63] Torrice, Antonio and Ro Logrippo *In My Room: Designing For and With Children.* New York: Fawcett Columbine 1989

health, colour has healing properties that have a direct effect on people's states of mind and physiology.[64] Torrice and Logrippo successfully applied this theory by designing a paediatric hospital playroom that had primary and secondary coloured spaces where young people were able to surround themselves with their colour of choice. These designers state that even a piece of coloured fabric introduced into a young persons environment could 'profoundly change' their outlook.[65]

'Little as we know about the way in which we are affected by form, by colour and light, we do know ... they have an actual physical effect. Variety of form and brilliancy of color in objects presented to patients are actual means of recovery.' Florence Nightingale 1888[66]

Research shows that colour also carries personal, symbolic, and cultural meanings that are specific to different individuals and groups of people over time.[67] The writer conducted an analysis of the colours of one of the popular teen publications - comic books. Results of this showed that comics use strong flat areas of cheaply process colour. This additive printing process produces a vibrant combination of pure primary and secondary colour in combination with a hot pink (magenta), a crisp lighter blue (cyan), and a lime green (yellow+cyan). Given the popularity of comic books among the adolescent population it could be inferred that adolescents would enjoy these bright processed colours.

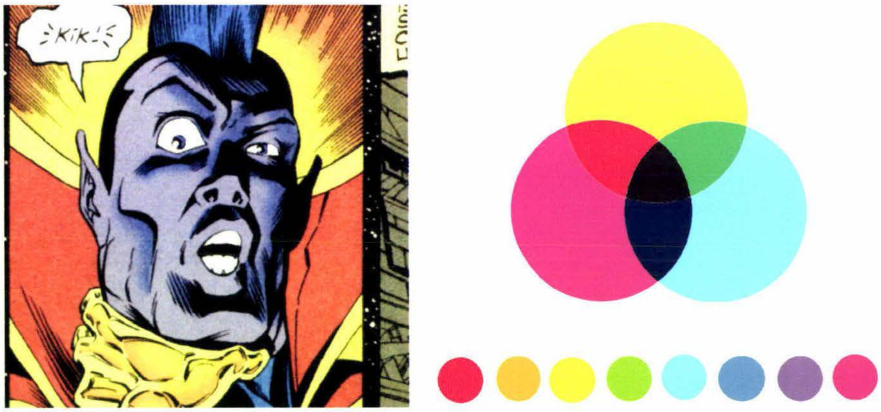

fig 2.5 process colour of comic books

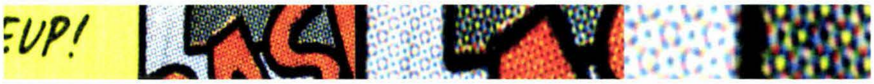

fig 2.6 magnified section of a comic

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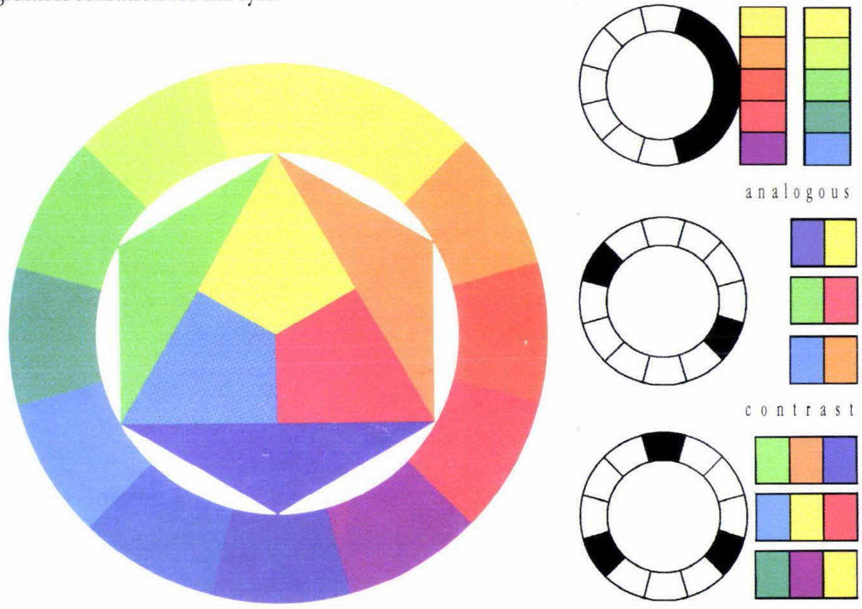
[64] Gage, John *Colour and Culture* London: Thames and Hudson

[65] Torrice, Antonio and Ro Logrippo *In My Room: Designing For and With Children.* New York: Fawcett Columbine 1989

[66] Nightingale, Florence in Chinn and Watson *Art and Aesthetics in Nursing* National League for Nursing press: New York 1994

[67] Gage, John *Colour and Culture* London: Thames and Hudson

Various logical and harmonious ways of combining the colours of the spectrum have been explored by colour theorists. According to Birren, numerous studies have shown that most people prefer orderly colour combinations where the colours are either closely related or where they are in marked contrast.[69] Birren describes the harmony of analogy as scales of closely related colours which are often found in nature (i.e. sunsets and rainbows), and the harmonies of contrast, which are generated by the use of complementary and triadic colours (fig 2.7).[68] Colour harmony has been described as any combination of colours chosen which are 'orderly in form and interval' when chosen from a colour sphere, with the likely result of creating an agreeable sensation for the eyes.[70]



analogous

contrast

triadic

fig 2.7 analogous, contrast and triadic colour

In a colour deprived environment like the hospital, the use of colour needs to be considered for its psychological and therapeutic qualities. This suggests that harmonious combinations of pure additive process colour would most likely be appealing as well as beneficial to adolescents. The literature also suggests that the visual surroundings of adolescent patients need to be considered in order to optimise their healing and recovery. The PIM can only go some way towards addressing these problems, as it cannot change the hospital environment itself. However, the content of the PIM can endeavour to give teenagers the opportunity to personalise their space and express their identity.

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[68] Birren, Faber. *The Principles of Colour.* New York: Van Nostrand Reinhold Co 1969

[69] Birren in Munsell *The Grammer of Colour* New York: Van Nostrand Reinhold Co 1969

[70] Cleland in Munsell *The Grammer of Colour* Ibid 1969

2.7.2 staff-patient relations

The main source of patient information in hospital is communicated verbally by nurses and doctors. Difficulties in communications between staff and patients has been shown to have a negative impact on a patient's treatment, and to lead to a lack of understanding, to misunderstandings and to distrust.[71] It is evident that the process of communication becomes harder when the sender and receiver of the messages come from different cultural and socio-economic backgrounds[72] as is often the case for communications between patients and staff members. To improve communications, it is necessary to understand the potential barriers to good communication, and to explore how these can be overcome.

One of the barriers is the complex job divisions within a public hospital which make it difficult for patients to get access to the most appropriate staff member for help or advice.[73] Whithorn observes that the people who know the most in hospital are often the least approachable.[74] It is during the doctors rounds that the opportunity arises to ask the most important questions. But because of the short time that doctors spend with patients it can be difficult for patients to remember and articulate the questions for which they most want answers. The relevance of Whithorn's observations for adolescent patients is confirmed in the findings of Cledon's survey which found that, although adolescents learnt most about their condition, treatment and progress from doctors, patients had limited access to doctors as adolescent patients mainly talked with other patients, visitors, parents and nurses. Cledon's findings led to a recommendation that doctors should spend more time talking with adolescent patients.

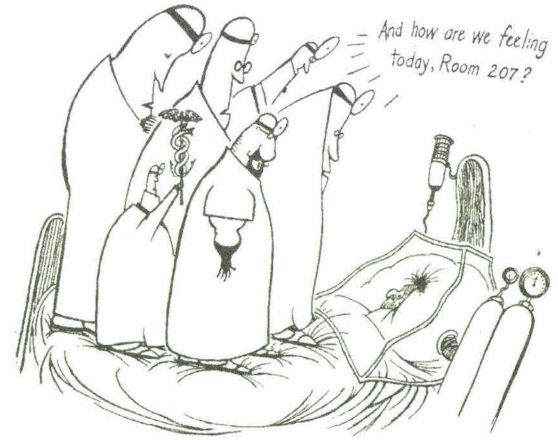

fig2.8 questioning doctors is not always easy

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[71] Pauwels Anne *Cross-Cultural Communication in the Health Sciences: Communicating with Migrant Patients* Melbourne: Macmillan Education 1995

[72] Fiske, John. *Introduction to Communications Studies.* Suffolk: The Chauser Press 1982

[73] Huttman, Barbara. *The Patient's Advocate: The Complete Book of Patient's Rights.* New Zealand 1981

[74] Whitehorn, Katherine. *How to Survive Hospital.* London: Butler and Thames Ltd 1972

Further barriers are cited in the adolescents themselves. There are a number of 'teenage' characteristics that make it hard for adolescents and hospital staff to talk with each other. Many health care providers report feeling under-trained and uncomfortable, and therefore reluctant to spend time dealing with young people.[75] 'They may be reasonable, helpful, cheerful, calm, and co-operative at one moment, and depressed, disruptive, demanding, manipulative, obstructionist, defiant or reject authority at others!'[76] These observations confirm the findings of the Haines survey that described adolescents as being cynical, disrespectful and that they tended to reject authority and institutions.[77] In addition to their dislike of authority, some adolescents actively refuse to communicate as a means of maintaining power in their situation[78] or simply because they are too scared to ask.[79]

Questioning is considered to be one of the most active tools patients have to help their own recovery.[80] It is important that patients perceive hospital staff realistically, and do not get trapped into the role of being a 'good' passive patient[81] who perceive the hospital staff as either 'personal servants' or 'godlike protectors'.[82] Instead they need to see the person behind the uniform and actively engage the staff in dialogue. The PIM could include an activity that explores patients and staff perceptions of each other.

The Royal Belfast Hospital in Ireland has successfully created a visual communications tool in the form of a Special Information Pack for Adolescents. This pack, designed specifically for younger adolescent patients, consisted of loose A4 pages on a range of topics (fig 2.9 and 2.11).

fig 2.9 the belfast adolescent patient pack

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75 New Opportunities in Delivery of Adolescent Health Services http:"www.mzxgp.org.nz/conf97/papers.htm

76 Bennett, D. *Growing Pains: What to do When Your Children Turn into Teenagers* Auckland: Hodder and Staughton Ltd NZ Ed 1987

77 Haines Recruitment Advertising. *A Presentation on Life as a 90's Teenager.* Wellington August 1997

78 Marris, M. *Teenagers: A Parent's Guide for the 90s* New Zealand: Tandem Press 1996

79 Morris, E. *Looking After Yourself: Some Views From 15-19 Year Olds on Health and Illness.* Special Report Series No 73 Wellington: Deparment of Health 1985

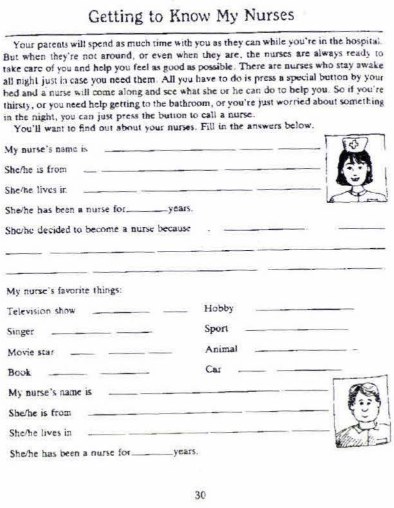
81 Ibid (Skipper)

82 Gots, Ronald and Arthur Kaufman. *The People's Hospital Book.* New York: General Pubishing Co 1978

As well as providing information on hospital staff, the forms are designed to help the adolescents collect information, compose questions, and give feedback to staff (fig2.11).

The Hospital Journal by Ann Banks also uses forms for the purpose of facilitation communications. As well as providing information on the role of nurses and how to use the bell to call for them, this journal provides spaces for the young patients to record information about the hospital staff, including their names, how long they had been working, why they became a nurse/ doctor, the staff member's favourite things (fig 2.10). It even gives the young patients a space to record 'what the doctor says about me getting better'.

These formats give adolescent patients a useful alternative to verbal communications. By formalising these 'conversation openers' into written forms, young patients are encouraged to interact with, and relate to staff members on a more social level. Dialogue at this basic and familiar level opens the channels of communication which in turn makes it easier for dialogue on symptoms, treatments, and any other concerns, to occur.[83]



Getting to Know My Nurses

Your parents will spend as much time with you as they can while you're in the hospital. But when they're not around, or even when they are, the nurses are always ready to take care of you and help you feel as good as possible. There are nurses who stay awake all night just in case you need them. All you have to do is press a special button by your bed and a nurse will come along and see what she or he can do to help you. So if you're thirsty, or you need help getting to the bathroom, or you're just worried about something in the night, you can just press the button to call a nurse.

You'll want to find out about your nurses. Fill in the answers below.

My nurse's name is ______

She/he is from ______

She/he lives in ______

She/he has been a nurse for ______ years.

She/he decided to become a nurse because ______

My nurse's favorite things:

Television show	______	Hobby	______
Singer	______	Sport	______
Movie star	______	Animal	______
Book	______	Car	______

My nurse's name is ______

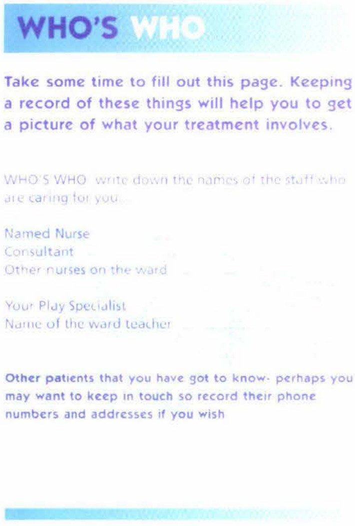
She/he is from ______

She/he lives in ______

She/he has been a nurse for ______ years.

30

fig 2.10 'staff' from the hospital journal



WHO'S WHO

Take some time to fill out this page. Keeping a record of these things will help you to get a picture of what your treatment involves.

WHO'S WHO write down the names of the staff who are caring for you...

Named Nurse
Consultant
Other nurses on the ward

Your Play Specialist
Name of the ward teacher

Other patients that you have got to know- perhaps you may want to keep in touch so record their phone numbers and addresses if you wish

fig 2.11 'staff' from the belfast pack

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[83] Fiske, John. *Introduction to Communications Studies.* Suffolk: The Chauser Press 1982

2.7.3 existing information

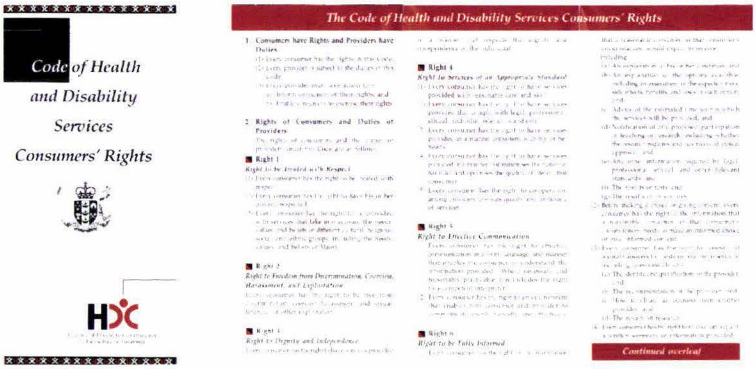
All patients require information about their responsibilities and rights as patients, the services that the hospital provides, and the role of hospital staff. Some of this information is already available to patients in the form of pamphlets and books (fig 2.12 and 2.13). Despite the fact that adolescent patients have their own distinct profile of design considerations and patient issues that need to be addressed, very little of this information is designed to be accessible to adolescents.

The health and disability services code of consumers' rights outlines patients' rights:[84]

The right to the information that a reasonable consumers', in that consumer's circumstances, would expect to receive...

The right to receive, on request, a written summary of information provided.

The right to effective communication in a form, language and manner that enables the consumer to understand the information. Health and Disability Commissioner 1998 [85]



Code of Health and Disability Services Consumers' Rights

The Code of Health and Disability Services Consumers' Rights

1 Consumers have Rights and Providers have Duties

2 Rights of Consumers and Duties of Providers

Right 1
Right to be Treated with Respect

Right 2
Right to Freedom from Discrimination, Coercion, Harassment, and Exploitation

Right 3
Right to Dignity and Independence

Right 4
Right to Services of an Appropriate Standard

Right 5
Right to Effective Communication

Right 6
Right to be Fully Informed

Continued overleaf

fig 2.12 pamphlet of consumers' rights

Another right that patients need to be aware of is the right to complain, as it is through complaints that patients can improve the quality of the services that they are offered.[86] McQuail notes that in hierarchical environments like hospitals, information more readily flows down from the centralised authority, while it is much harder for criticism and complaints to work their way up the system.[87] It is especially hard for patients who are a dependent, captive, and transient population, to complain without fear of retribution from their care givers.

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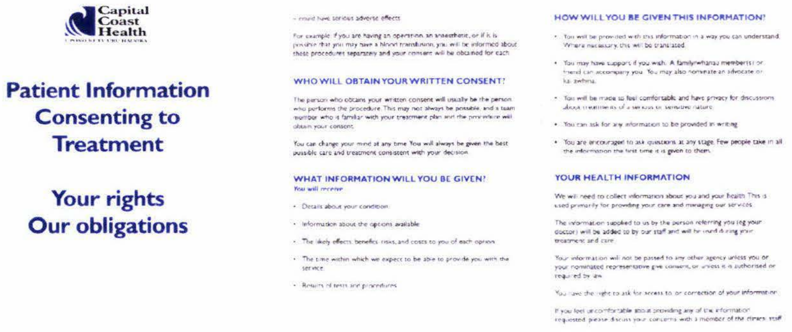
[84] Merrill, Sarah Bishop. *Defining Personhood: Towards the Ethics of Quality in Clinical Care.* Amsterdam: Rodopi Value Inquiry Book Series 70 1994

[85] Health and Disability Commissioner *Code of Health and Disability Services Consumers' Rights* New Zealand 1998

[86] Leshan, Lawrence. *The Mechanic and the Gardener: Making the Most of the Holistic Revolution in Medicine.* New York: Holt, Rinehart and Winston 1982.

[87] Mcquail, Denis. *Communication* New York: Longman Inc 1975



Capital
Coast
Health

Patient Information Consenting to Treatment

Your rights Our obligations

– could have serious adverse effects

For example: if you are having an operation, an anaesthetic, or if it is possible that you may have a blood transfusion, you will be informed about these procedures separately and your consent will be obtained for each.

WHO WILL OBTAIN YOUR WRITTEN CONSENT?

The person who obtains your written consent will usually be the person who performs the procedure. This may not always be possible, and a team member who is familiar with your treatment plan and the procedure will obtain your consent.

You can change your mind at any time. You will always be given the best possible care and treatment consistent with your decision.

WHAT INFORMATION WILL YOU BE GIVEN?
You will receive:

- Details about your condition
- Information about the options available
- The likely effects, benefits, risks, and costs to you of each option
- The time within which we expect to be able to provide you with the service
- Results of tests and procedures

HOW WILL YOU BE GIVEN THIS INFORMATION?

- You will be provided with this information in a way you can understand. Where necessary, this will be translated.
- You may have support if you wish. A family/whanau member(s) or friend can accompany you. You may also nominate an advocate or kai awhina.
- You will be made to feel comfortable and have privacy for discussions about treatments of a serious or sensitive nature.
- You can ask for any information to be provided in writing.
- You are encouraged to ask questions at any stage. Few people take in all the information the first time it is given to them.

YOUR HEALTH INFORMATION

We will need to collect information about you and your health. This is used primarily for providing your care and managing our services.

The information supplied to us by the person referring you (eg your doctor) will be added to by our staff and will be used during your treatment and care.

Your information will not be passed to any other agency unless you or your nominated representative give consent, or unless it is authorised or required by law.

You have the right to ask for access to, or correction of your information.

If you feel uncomfortable about providing any of the information requested, please discuss your concerns with a member of the clinical staff.

fig 2.13 pamphlet of patients' rights

It is during the adolescent years that patients are mentally and legally able to fully exercise their rights as they take control of their own health care for the first time. (After the age of sixteen, parents or guardians are no longer asked to give consent on behalf of a young person who is about to undergo anaesthesia or medical procedure).[88] [89] Although those over the age of sixteen have more responsibility for their health care, patients of all ages benefit from knowing their rights in relation to the information they receive. [90] The degree to which adolescent patients are involved in their treatment is also dependant on their level of maturity and (as with all other patients) their willingness to be involved in the process of making decisions. It has been found that many adolescent patients are eager to be informed and to make decisions about their health care.[91]

It has been found that adolescents are more likely to comply with treatment when they have a sound knowledge of causality and prognosis.[92] [93] Many adolescents have been observed to act on the attitude that 'It's my body and I'll do what I like with it!'[94] As a result, non-compliance with treatment is one of the major problems that hospital staff face in dealing with young patients.[95] Therefore it is extremely important that adolescent patients feel as if they are informed and involved in their treatment. The available information, therefore, needs to be presented in a form and manner which adolescents' are familiar with and will understand.

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[88] Reid, J. "The Young Person and the Family Doctor". In: *Health in Adolescence and Youth:* Proceedings of the second annual Symposium of the Friends of the Otago Medical School Trust. Otago: Otago Medical School, p33 1985

[89] Maskill, C. *Health Profile of New Zealand Adolescents.* Wellington: Department of Health 1991

[90] Fitzsimmins, C. Creating a Special Information Pack for Adolescents in Hospital. *Nursing Times.* June 9, Vol 95, No 23 1999

[91] Cledon et al. *Is Dunedin Hospital Suited to Adolescent Patients?* Otago: University of Otago 1986

[92] Shenker et al. Adolescent Medicine. Monographs in *Clinical Pediatrics No 7* Switzerland: Harwood Academic Pub 1994

[93] Moyers, Bill. *Healing and the Mind.* London: Harper Collins 1993

[94] Morris, E. *Looking After Yourself: Some Views From 15-19 Year Olds on Health and Illness.* Special Report Series No 73 Wellington: Deparment of Health 1985

[95] Muir, R. 1985. "Health Services for the Adolescent". In: *Health in Adolescence and Youth: Proceedings of the Second Annual Symposium of the Friends of the Otago Medical School Trust.* Otago: Otago Medical School. Pp. 28-31.

Written information is often supplied to patients in the form of pamphlets designed for the use of the general adult public. These pamphlets contain information about patients' rights, the hospital and hospital services, and are either given directly to patients or displayed on information stands throughout hospitals. Some wards generate and collate these pamphlets into ward folders. Across a range of hospitals blue was used as a key colour for their logo identity. The hospital information pamphlets mainly consist of one or two colour, densely worded, A4 pages folded in thirds. The logo design on the cover being the only outstanding graphic element (fig 2.14-5).

Auckland Healthcare

Notice to All Patients

*If you **were** born in New Zealand*

If you were born in New Zealand or are now a citizen or permanent resident of New Zealand, the charges for hospital visits are as follows:

Outpatient	Adult $31	Child $16
Daypatient	Adult $31	Child $16
Inpatient	No charge	No charge

You will be charged for a maximum of five outpatient or daypatient visits in any one health year (1 February to 31 January).

You are exempt from these charges if you hold a Community Services or High User Card valid at the time of your visit, and in some other circumstances.

You will be asked to produce your card or other proof of a right to an exemption.

*If you **were not** born in New Zealand*

If you were not born in New Zealand, you may still be eligible for health care at New Zealand resident rates.

To prove eligibility you are required to produce your passport at the time of your clinic attendance or admission.

If you are unable to produce evidence of New Zealand residency, you will be charged at the non New Zealand resident rate.

If you are not sure about your entitlement to health care or you want to find out how much you will be charged, please discuss this with the clerk or you can call the Revenue Office through the hospital or service telephone exchange.

Capital Coast Health
Wellington Hospital

Information

Outpatient Services

Outpatient Clinics

fig 2.14 patient information pamphlets

Welcome to Wellington Hospital

PATIENT INFORMATION

Capital Coast Health

MEDICAL INFORMATION

CLOTHING/LAUNDRY

MEALS

LEAVING THE WARD

TEACHING

VOLUNTEERS/LIBRARY SERVICE

OTHER SERVICES

DAILY ACTIVITIES

GENERAL INFORMATION

fig 2.15 patient information pamphlets

When these pamphlets were compared to pamphlets designed for adolescent patients it becomes clear that none of these pamphlets were designed with adolescent patients in mind. The pamphlets targeting adolescents were very different to these general pamphlets. The adolescent's pamphlets tended to be full colour booklets and employ the graphic language of comic books with a predominance of illustration and comic book features including speech bubbles (fig 2.16-7). Cartoon and comic illustrations and formats have been considered to have a number of advantages when communicating with adolescents. Not only are they popular with this age

fig 2.16 'spin' ministry of youth affairs

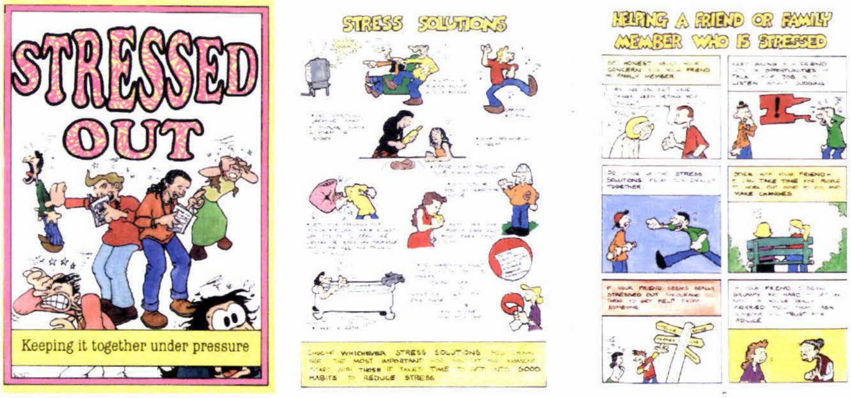

fig 2.17 'stressed out' ministry of health

group, but the emphasis on illustration and use of narrative make communications understandable to a wider audience. According to Fiske, communications based on images have been found to be more powerful than words in rousing emotions and in reinforcing memory. Both comics and cartoons can convey a wealth of information simply and directly.[96] These formats use a sequence of narrative images very similar to television/film media and are, therefore, more likely to appeal to the tastes of adolescents who have grown up with audio-visual media. [97] It is interesting to note that some schools in Britain are replacing traditional reading texts with comics and graphic novels for the purpose of encouraging their pupils to read more.[98]

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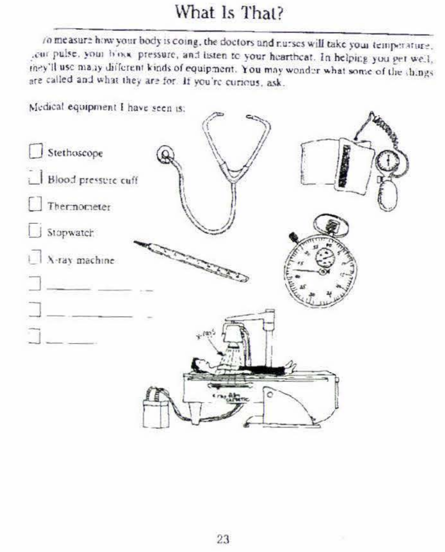
[96] Freedberg, David. *The Power of Images: Studies in the History and Theory of Response* Chicago University of Chicago 1989

[97] Gombrich, E H *The Image and the Eye: Further Studies in the Psychology of Pictorial Representation.* Oxford: Phaidon Press 1982

[98] Sunday Telegraph. Schools Replace Novels with Comics *The Dominion.* Dec 21 1998

Many of the publications currently available for adolescents in hospital are outdated, poorly designed and target a younger audience. It appears that these publications are generated and designed by health professionals without using the skills of trained designers and illustrators. While these publications contain vital information and are in constant use in hospitals, most of them show no consideration or experimentation in their use of type and illustration. They tend to use standard serif and san-serif type faces for both their titles and body copy and the placement of type and illustration is often not integrated. As can be seen in the examples on this page, the illustrations are also poorly executed, lacking in observational accuracy and variety in the use of line, tone, and composition (fig 2.18 and fig 2.19).



What Is That?

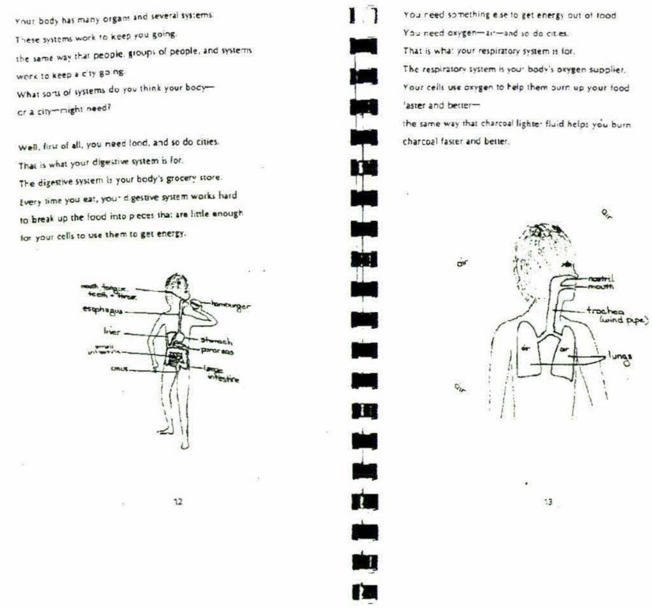
To measure how your body is doing, the doctors and nurses will take your temperature, your pulse, your blood pressure, and listen to your heartbeat. In helping you get well, they'll use many different kinds of equipment. You may wonder what some of the things are called and what they are for. If you're curious, ask.

Medical equipment I have seen is:

☐ Stethoscope
☐ Blood pressure cuff
☐ Thermometer
☐ Stopwatch
☐ X-ray machine
☐ ______
☐ ______
☐ ______

23

fig 2.18 examples of existing illustrations



Your body has many organs and several systems.
These systems work to keep you going
the same way that people, groups of people, and systems
work to keep a city going.
What sorts of systems do you think your body—
or a city—might need?

Well, first of all, you need food, and so do cities.
That is what your digestive system is for.
The digestive system is your body's grocery store.
Every time you eat, your digestive system works hard
to break up the food into pieces that are little enough
for your cells to use them to get energy.

12

You need something else to get energy out of food.
You need oxygen—air—and so do cities.
That is what your respiratory system is for.
The respiratory system is your body's oxygen supplier.
Your cells use oxygen to help them burn up your food
faster and better—
the same way that charcoal lighter fluid helps you burn
charcoal faster and better.

13

fig 2.19 examples of existing illustrations

fig 2.20 graphic design by Sher and Brody

The lack of quality in existing patients' information becomes clear when they are compared to the use of image, space, tone, and type of the work of contemporary magazine and youth designers like Carson, Brody, and Scher (fig 2.20-1). Their graphic styles demonstrate the impact that can be made with a more experimental and inventive application to integrating illustration, type, and graphic elements. The bold use of dark tone in these examples helps to emphasise the textural qualities of type.

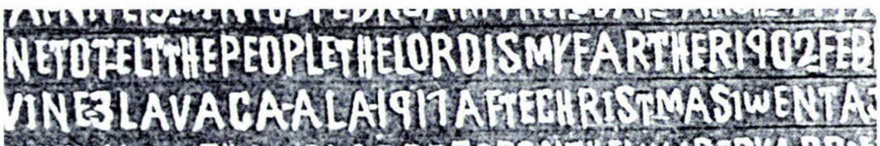


fig 2.21 example of text cited in Carson

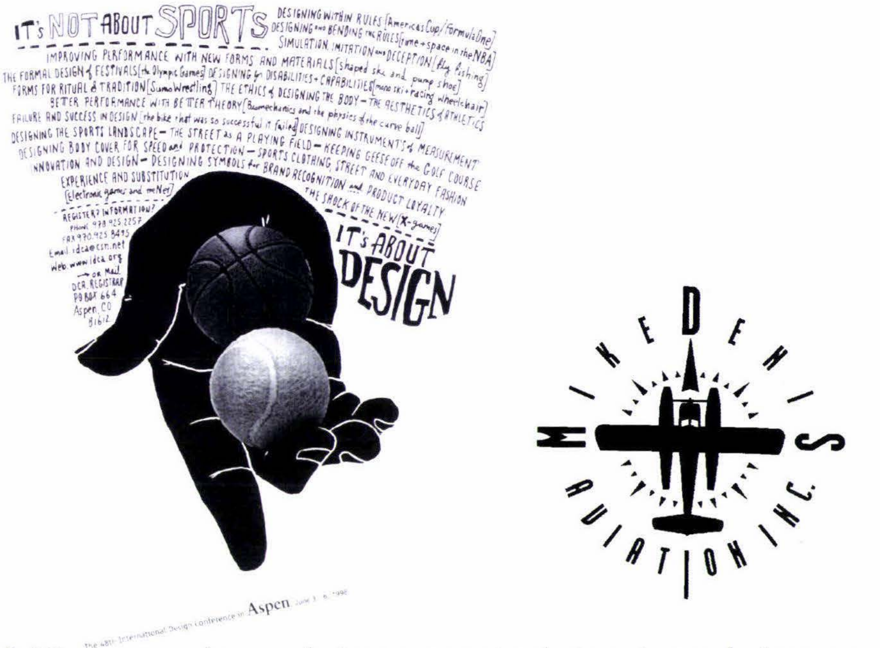


fig 2.22 examples of integrated text and image

Brody points out that each typeface has its own distinct personality and 'air of its own.' He suggests that designers should list the attributes required for their project, then seek typefaces that display those attributes.[99] For the purposes of this project it was important that the design of the type broke away from the conservative tradition of hospital information design, and displayed some of the graphic qualities associated with teenage rebellion. So it seemed logical to consider the graphic style of graffiti as it is often associated with adolescents. The designer studied graffiti from the local geographic area to better consider its graphic qualities (fig 2.23).

fig 2.23 photo documentary of graffiti

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[99] Brody, Neville. *The Graphic Language of Neville Brody* London: Thames and Hudson 1988

It was observed that the combinations of carefree scratching, scribbling and dripping of the graffiti created a lively and interesting variety of shapes and surface textures. These qualities can also be found in the graphic hand writing styles of Fletcher and Steadman (fig 2.24).

fig 2.24 text by Steadman and Fletcher

While Carson states that there is no such thing as a successful style for youth design[100] he does suggest integrating the form and content so that the use of type and images help to intelligently express the messages or contents.[101] The Haines survey also concluded that there is no universal style that would currently work for teenagers. More specifically they noted that designs that were patronising, or tried to be trendy, had a high chance of failing. Because adolescents associate themselves with a vast array of different 'global tribes' adhering to any well established style would only appeal to a small proportion of adolescents.

Instead the Haines survey findings suggested that designers should be honest and original in both their ideas and approach, and if possible, should include the element of surprise. It was also pointed out that adolescents like to be seen as 'street smart' and treated as intelligent people.[102]

The lack of existing information designed specifically for adolescent patients can hinder their understanding of their treatment and rights and thereby contributes to adolescents patients rejection of authority and tendency not to comply with treatment. It is therefore important that information is designed to be accessible to them. From existing examples of design for adolescent

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[100] Trapp, Doug Carson Redesigns Medium by Medium http://132.235.238.184/archives/032896/carson.html

[101] Carson, David. David Carson; 2nd site, New York, Rizzoli, 1996.

[102] Haines Recruitment Advertising. *A Presentation on Life as a 90's Teenager.* Wellington August 1997

patients it is possible to infer that an intelligent, experimental and playful use of colour, illustration, and type would improve communications with this age group.

2.7.4 games and activities

Some of the books designed to help children cope with the experience of being in hospital contain activities and games that are designed to inform, entertain, and help pass the time.

The literature revealed that many adolescent patients feel bored in hospital. Half of the patients in the Cledon survey said they felt bored; some of them mentioned that they disliked feeling confined and frequently found themselves with nothing to do.[103] Kimpton, in her survival book for young patients, points out that feeling bored is a natural reaction to having to wait; waiting for tests, waiting for doctors, waiting for results, and waiting to get better.[104] People perceive time as moving slowly when they are waiting for something to happen. Arnheim suggests that this is because they are marking time between now and the anticipated event and therefore are not engaged in the activities around them.[105] This process is even harder for adolescents who tend to get bored quickly.[106]

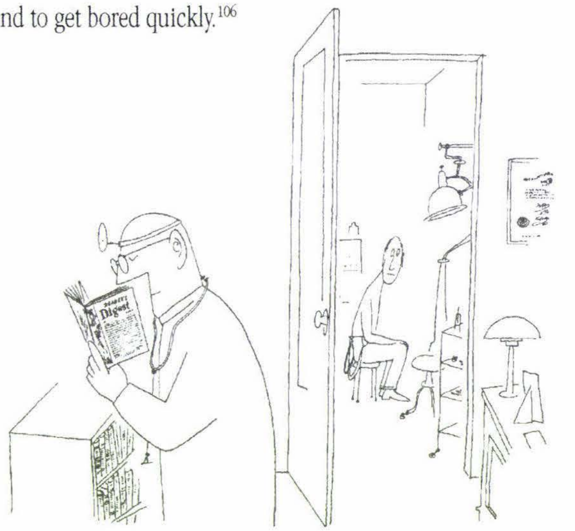

fig 2.25 patients are constantly kept waiting

Boredom could also be due to the lack of educational and recreational activities available for adolescents. Children's activity needs are often met in hospital by Hospital Teachers and Play/ Recreational Therapists. Most often these health specialists are not trained to cope with adolescents so their recreational and educational needs can be overlooked (especially adolescents

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[103] Cledon et al. *Is Dunedin Hospital Suited to Adolescent Patients?* Otago: University of Otago 1986

[104] Kimpton, Diana. *The Hospital Highway Code: An Invaluable Guide for Every Young Patient.* London Pan Macmillan 1994

[105] Arnheim, Rudolf. *Art and Visual Perception: A Psychology of the Creative Eye.* London: Faber and Faber 1964

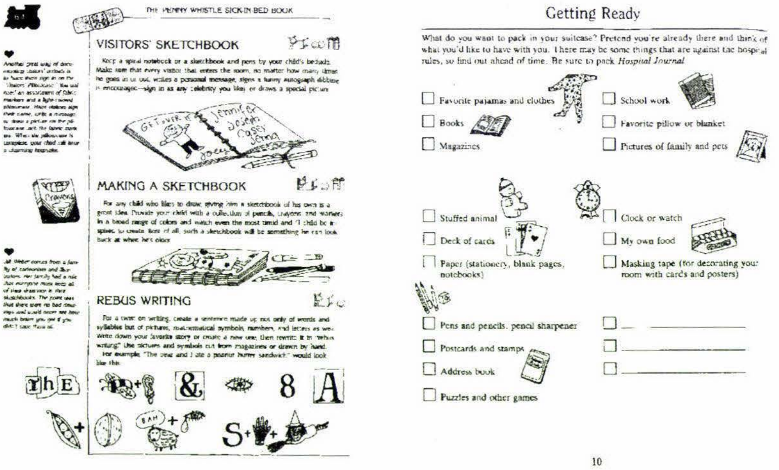
[106] Haines Recruitment Advertising. *A Presentation on Life as a 90's Teenager.* Wellington August 1997

on adult wards).[107] There is a perception that adolescents no longer need activities and games because playing is only for children. Harvey et al note that this perception can negatively affect the provisions made for adolescents in hospital.[108]

As well as being engaging and enjoyable, play has been shown to have therapeutic properties. Through the activity of play, people are able to create a symbolic world where they can safely overcome frightening feelings, symbolically triumph over upsets, and deal with traumas.[109] Erikson suggests that through play, people are able to resolve past, present and future experiences and possibilities, thereby taking some control of their lives.[110] Gregory also talks about being able to learn through play and suggests that adults should continue to learn through play all through their lives.[111]

It has been suggested by medical specialists that adolescent patients would benefit from a wide range of activities.[112] The following books suggest the sorts of activities that patients in hospital would find most useful to pass the time. They recommend a combination of problem solving games (puzzles, crosswords, anagrams), creative activities (drawing, writing) and solitary recreational pursuits (books, tapes, playing cards, electronic games) (fig 2.26).

Hospital Journal: A Kids Guide to a Strange Place. by Ann Banks Puffin: London 1989
The Hospital Highway Code: An Invaluable Guide for Every Young Patient by Diana Kimpton London: Pan MacMillan, 1994
How to Survive Hospital by Katharine Whitehorn London: Butler and Thames Ltd. 1972
The Penny Whistle Sick-In-Bed Book by Meredith Brokaw and Annie Gilbar 1993



THE PENNY WHISTLE SICK-IN-BED BOOK

VISITORS' SKETCHBOOK

Keep a spiral notebook or a sketchbook and pens by your child's bedside. Make sure that every visitor that enters the room, no matter how many times he goes in or out, writes a personal message, signs a funny autograph (fibbing is encouraged—sign in as any celebrity you like) or draws a special picture.

MAKING A SKETCHBOOK

For any child who likes to draw, giving him a sketchbook of his own is a great idea. Provide your child with a collection of pencils, crayons and markers in a broad range of colors and watch even the most timid and ill child be inspired to create. Best of all, such a sketchbook will be something he can look back at when he's older.

REBUS WRITING

For a twist on writing, create a sentence made up not only of words and syllables but of pictures, mathematical symbols, numbers, and letters as well. Write down your favorite story or create a new one, then rewrite it in "rebus writing." Use pictures and symbols cut from magazines or drawn by hand.
For example, "The bear and I ate a peanut butter sandwich" would look like this:

Getting Ready

What do you want to pack in your suitcase? Pretend you're already there and think of what you'd like to have with you. There may be some things that are against the hospital rules, so find out ahead of time. Be sure to pack *Hospital Journal*.

☐ Favorite pajamas and clothes
☐ Books
☐ Magazines
☐ School work
☐ Favorite pillow or blanket
☐ Pictures of family and pets
☐ Stuffed animal
☐ Deck of cards
☐ Paper (stationery, blank pages, notebooks)
☐ Clock or watch
☐ My own food
☐ Masking tape (for decorating your room with cards and posters)
☐ Pens and pencils, pencil sharpener
☐ Postcards and stamps
☐ Address book
☐ Puzzles and other games
☐ ____________
☐ ____________
☐ ____________

10

fig 2.26 suggestions for activities and games

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107 McClellan, Velma. *Adolescent Health: Current Issues.* Wellington: Department of Health 1990.

108 Harvey, D. et al. *Hospital: A Deprived Place for Children.* A Case for Hospital Play Schemes. London: Save the Children 1984

109 What is Play Theapyhttp://ww.snowcrest.net/kidpower/play.html

110 Erikson, Erik. *Toys and Reasons: Stages in the Ritualisation of Experience.* New York: W.W. Norton and Company inc 1977

111 Gregory, Richard *Mirrors in Mind.* London: Penguin Group 1997

112 Medlicott, T.. "Handicap and Chronic Ill Health". In: *Health in Adolescence and Youth:* Proceedings of the Second Annual Symposium of the Friends of the Otago Medical School Trust. Otago: Otago Medical School. Pp17-18. 1985

Fiske's research shows that different media satisfy different needs. Books and films are used by people to escape from their reality, while radio and television help people to feel connected to society. The literature also notes that those with less education prefer electronic and visual media to print media.[113] When people of any age become sick, they need materials that are simple, familiar, and easy to understand. When ill, patients tend to regress to a younger stage. Whitehorn even suggests supplying adult patients with children's books and puzzles.[114] Paper puzzles are particularly useful in the hospital environment because they tend to be cheap, easy to store and have no electronic components that could interfere with medical equipment. Some examples of paper games include folding games, vanishing puzzles and mazes (fig 2.27-8).

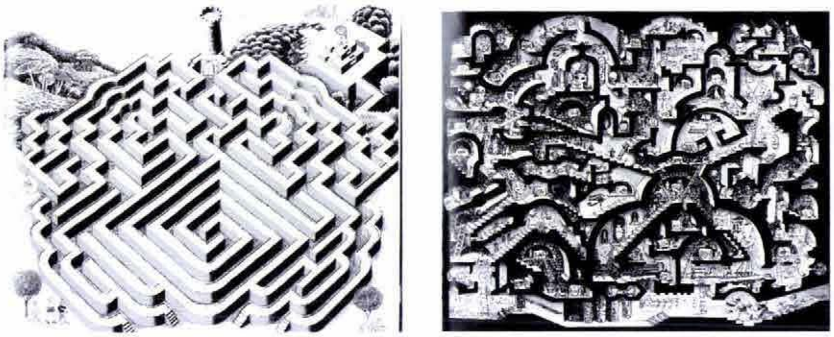

fig 2.27 examples of mazes

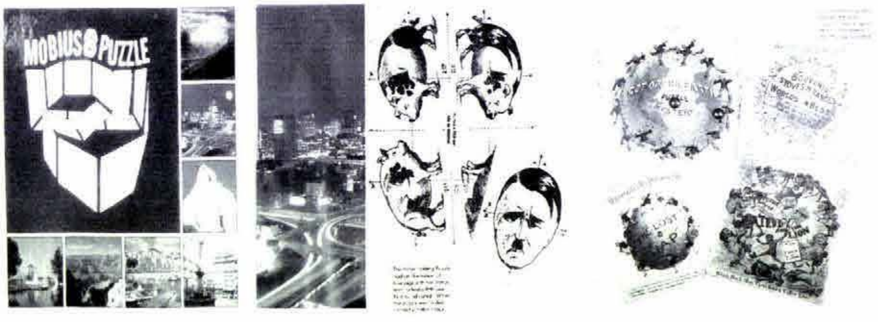

fig 2.28 examples of paper folding games

It is clear from the literature that engaging adolescent patients in play would be worthwhile as it would alleviate their boredom and increase their enjoyment. It also has the potential to give them an opportunity to work through some of the more upsetting aspects of being hospitalised. This suggests that it would be useful to design information as games or activities and include these in the PIM.

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[113] Fiske, John. *Introduction to Communication Studies*. Suffolk: The Chauser Press 1982

[114] Whitehorn, Katharine. *How to Survive Hospital*. London: Butler and Thames Ltd 1972

2.7.5 creative expression

To fully address adolescent needs it is also necessary to consider their social, emotional, and creative needs. Considering people's creative and expressive needs brings us back to Archer and Papanek's theory of good design (to provide people with the opportunity to be active in solving their own problems and to become, in a sense, their own designers). Shedroff talks about the value of using 'creation tools' to design useful experiences for people. He maintains that:

'few products are designed to grow or become more valuable over time with participation from the audience. Yet, products that help users structure their experiences and share their knowledge are inherently more valuable than those which do not'. Nathan Shedroff 1994[116]

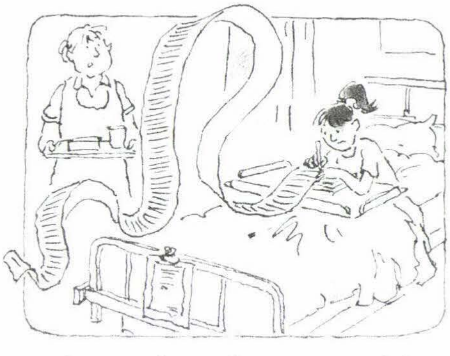

fig 2.29 patients benefit from self expression

To establish what sort of creative tools would be beneficial to adolescents, their psychological and emotional experiences were considered. Loss of autonomy and self esteem, fear of isolation, possibility of painful procedures, and the prospect of being disrobed are all causes of anxiety for patients, and especially for adolescents who are easily embarrassed.[117] [118] Many adolescent patients go through a grieving process.[119] Numbness, sadness, depression, guilt, anger, fear, and relief are some of the well-documented stages of this process. The grieving process can be especially difficult for adolescents because they do not yet have enough experience to put events into perspective and many experience intense emotional cycles.[120] These difficulties are compounded by the isolation of adolescent patients from their peers, and by their tendency to reject adult support.[121]

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[115] Cledon et al. *Is Dunedin Hospital Suited to Adolescent Patients?* Otago: University of Otago 1986

[116] Shedroff, Nathan (1994)): *Inforamtion Interaction Design: A Unified Field Theory of Design*. [www document] http://www.nathan,com/thoughts/unified/index.html [8/10/99]

[117] Bertman, Sandra L. *Facing Death: Images, Insights, and Interventions.* Massachusetts: Hemisphere Publishing Co. 199.

[118] Starbright http://www/starbright.org/projects/rsch-goals.html

[119] Kubler-Ross and Horowitz in Smith Smith, Dorothy W. *Survival of Illness: Implications for nursing*. New York: Springer Publishing., 1981

[120] Percival, Anne. Traumatic Events in the Lives of Adolescents *Paediatric Nursing* July Vol II No 6 1999

[121] Tonkin, Lois. *Everybody Hurts Sometimes: A Book about Grief for Children and Teenagers* Christchurch: Port Hills Press 1997

Having the support of friends is important for adolescents who often rely more on peer support than on the support of their own families. This is particularly the case in the current New Zealand social climate. At present many adolescents experience home as a stressful place because of a high prevalence of broken families, working mothers, and for some, the responsibilities of caring for younger siblings.[122] For these young people their peer group is their main support. Cledon found that half of the adolescents surveyed felt isolated, and said that they needed someone to talk to about their problems in hospital.[123]

Some hospitals overseas have been able to foster a sense of community among their adolescent patients by facilitating support groups within hospitals. These groups offer young people an opportunity to meet to discuss adolescent and health issues.[124] Adolescents benefit greatly from being able to tell their own stories. They also benefit from hearing the stories of other people their own age who have already experienced what they are going through.[125] [126] When it is not possible to physically bring patients together, it is necessary to find alternative ways that adolescents can safely and appropriately share their experiences and express themselves.[127]

The PIM, therefore, needs to supply patients with creative activities that are designed to facilitate self-expression. Robyn Hart et al suggest adolescent patients would benefit from writing about their thoughts, feelings and experiences. Some of the examples they give are: writing or drawing on a graffiti board, writing a letter to their doctor or for a hospital newsletter.[128] The PIM itself be designed to collect the stories of adolescent patients.

For adolescent patients who are often isolated from their peers and tend to suffer from low self esteem, being offered a creative means to share their experiences and express their emotions would be a useful contribution to their emotional well-being while in hospital.

2.8 summary

Literature on the designer as author/producer and on user-centred research provided a rationale for the identification of the needs of adolescent patients, and to develop solutions to meet those needs.

Research identified key factors likely to contribute to the health care and healing processes of adolescent patients. It was found that the hospital surroundings can contribute to making

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[122] Haines Recruitment Advertising. *A Presentation on Life as a 90's Teenager.* Wellington August 1997

[123] Cledon et al. *Is Dunedin Hospital Suited to Adolescent Patients?* Otago: University of Otago 1986

[124] Adolescent Peer Support ACU RAP Group Vancouver

[125] Moyers, Bill. *Healing and the MInd.* London: Harper Collins 1993

[126] Kleinman, Arthur. *The Illness Narratives*

[127] Whitehouse, Elaine and Pudney, Warwick. *A Volcano in My Tummy: Helping Children to Handle Anger* New Zealand: Foundation for Peace Studies in Aotearoa 1994

[128] Hart, Robyn et al *Therapeutic Play Activities for Hospitalised Children* 1992

adolescent patients feel alienated and unwelcome in hospital and that adolescent must overcome significant barriers to communicate effectively with hospital staff. It was also found that existing hospital information was not designed for this age group and did not address their needs.

To determine if these factors were being addressed in the New Zealand public hospital system research was also conducted in hospitals through interviews and surveys. This would help to ensure that the PIM would be relevant to the current situations of adolescent patients and to identify any issues not picked up by the literature review. The methodology for this is described in the following chapter.

methodology

3

Designers should get to know their audience, and seek their opinions, even meet and talk with them where they live and work. D. Hales 1994[1]

To understand and record the experiences, opinions and needs of adolescent patients and their care givers, the designer conducted research in the hospital environment. The adolescent patients were surveyed using a questionnaire, and the hospital staff were interviewed. The information sheets, consent forms, and questionnaire used for this research can be found on pages 38-46 amd 49-50). An outline of the complex and rigorous process of gaining approval to conduct this research, along with descriptions of the questionnaires and interviewing methods used are presented below.

To obtain a representative sample of patients in New Zealand, three hospitals were chosen.

Wellington Hospital (Wellington)

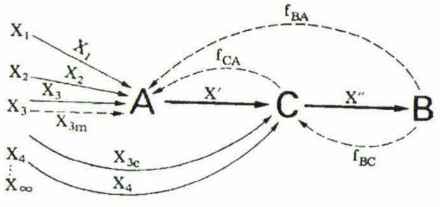
Middlemore Hospital (Auckland)

The Childrens‘Starship Hospital (Auckland)

Although most of the research took place in the paediatric wards of the three hospitals, research was also conducted on a variety of specialist adult wards which admitted adolescent patients. These included: Oncology, Orthopaedics, Nephrology, General Surgery, and General Medicine.

3.1 gaining approval

The relationship between the designer and the patient is not direct but is necessarily mediated by the hospital system. Because the hospital staff control the nature and content of information given to patients the designer must address the interests and needs of adolescent patients as they are perceived by hospital staff.[2] The Westley and MacLean model of mass communication can be used to express the relationship between the designer/producer, the hospital administration/staff and the patient (fig 3.1).[3]



A: the would-be communicator or ‘advocate’ (the designer/producer)
B: the audience member (the adolescent patient)
C: the mass communication organisation and its agents who control the channels (the administration and staff of the hospital)
X: any event or object in the environment of A, B, or C which is a subject of communications
f: feedback

fig 3.1 Westley and MacLean - communications

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[1] Hales, D. ‘Evaluating Design the Non-Linear Way’ *AIGA: Journal of Graphic Design*. Vol 12 No. 3 p34 1994
[2] Fiske, John. *Introduction to Communication Studies*. Suffolk: The Chauser Press 1982
[3] McQuail, Denis. *Communication*. New York: Longman Inc 1975

How information is controlled in hospitals becomes evident in the process of gaining approval to conduct research. Bogden and Taylor warn that it can be difficult to gain access to conduct research in large bureaucracies as it is often necessary to gain approval from 'gatekeepers' at each level of an organisation.[4] This proved to be the case in gaining access to patients in hospitals in New Zealand.

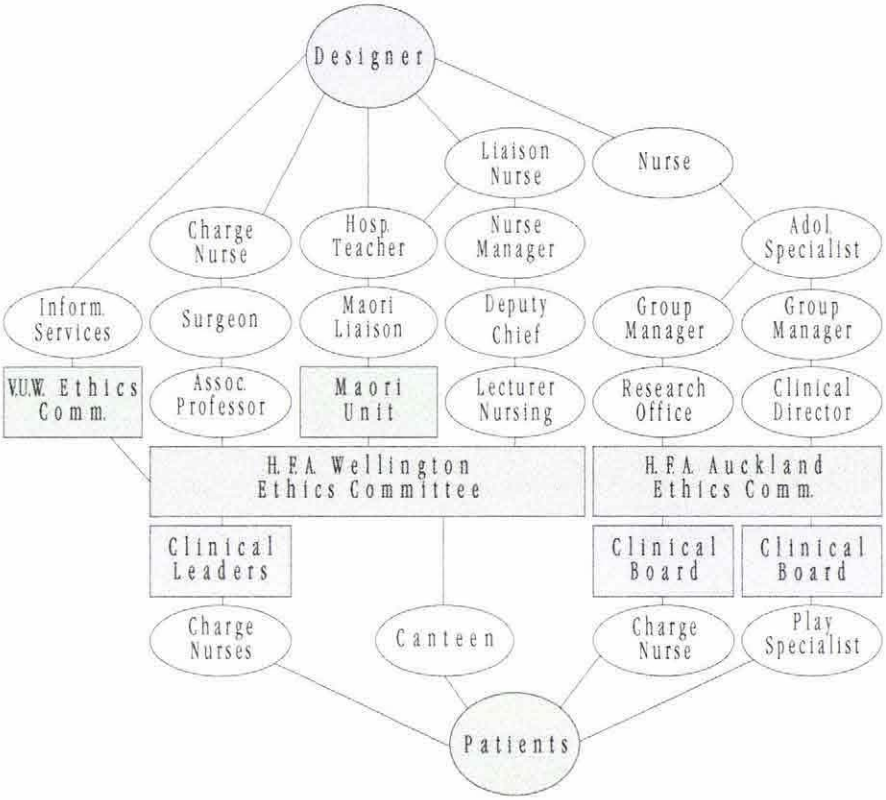

fig3.2 individuals/committees approached

Before it was possible to conduct the research, it was necessary to gain approval from the following: Victoria University University Ethics Committee; Managers from each hospital to support the application to the HFA Ethics Committees; The Health Funding Authority Ethics Committees to ensure that the proposal is sound and ethically appropriate for use in hospitals. Ethical approval from both Wellington and Auckland Health Funding Authority Ethics Committees; Clinical Boards and/or the Clinical Leaders in each hospital; Charge Nurses and the Nurses of the Patients; Legal Guardians of the Patients (if the patient was under 16 years old); Maori Research Officer from a Hospitals Maori Unit; and last, but not least, the Patients themselves.

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[4] Bogden, R. and S. Taylor *Introduction to Quantitative Research Methods*. New York: John Wiley & Sons: p15-17 1975

As an outsider to the health system it proved difficult to gain an overall perspective of all the required approvals in advance. It was only at each stage of gaining approval that the next stage became apparent. This made the process unexpectedly time consuming and frustrating. The application for Health Funding Authority (HFA) Ethical approval included designing questions/questionnaires, information sheets, and consent forms that met the HFA's regulations. It also required completing a 17 page form that detailed the nature of the research, and outlined issues relating to resources, confidentiality, consent, and culture. Ultimately an additional six months was required to achieve all the necessary approvals before interviewing and surveying could commence. Because of the *Privacy Act* it was not possible to include participants from the Cancer and Arthritis societies. However, as this project progressed the researcher made contact with Canteen (Cancer support group for teenagers) and in the context of the work being undertaken in hospital, Canteen members were able to be included in this research.

Future design students should be aware that an extensive amount of time, travel, and correspondence could be required to undertake research in the health sector particularly if their project requires approval from more than one ethical committee. As the designer worked through the processes of receiving approval, however, it became apparent that there were many benefits to be gained including:

gaining credibility as an outsider by displaying a willingness to comply with the procedures and protocols of the institution

being able to state with authority that the content covered and the processes used were appropriate for, and valuable to the institution

being given authority to discuss this project with members at all levels of the organisation and thereby gaining support for the project and its outcomes

gaining the opportunity to raise awareness of the problems adolescent patients face in hospital.

Gaining Ethical Approval from the Regional Health Authorities was not only necessary, but helped to provide rigour in the quality and relevance of the questions asked, and consequently in the answers received, the identification of issues and the development of solutions which will have practical application in Hospitals in New Zealand.

3.2 patients questionnaire

To inform the designer of the context in which the PIM would be used, and to define the issues the PIM would seek to address it was necessary to learn about patients' needs from the patients themselves. Ford and Walsh suggest that it is possible to develop a more accurate picture of patients' experiences by questioning them about their specific feelings, such as pain and anxiety rather than asking more generalised questions.[6]

The adolescents chosen for this study would be classified as injured and ill, so it was important that the method of data collection was as unobtrusive and user-friendly as possible. To make the questionnaire easy to use, most of the questions were designed using seven point scales that allowed the patient to indicate the strength of their feeling or opinion simply by ticking a box. However, using attitude scales made it possible to measure the strength of these feelings or opinions but not their causes. To make the section on patients' perceptions more open-ended, a space was provided under each scale where the patient could explain or illustrate their response by giving examples.

After being introduced to the patients, the designer explained the nature of the project, the contents of the questionnaire, the consent form, and information sheet page 51. The patients were then given the option of completing the questionnaire that day for it to be collected, or of returning it in their own time in the stamped self-addressed envelope provided.

3.2.1 pilot test

Once the questionnaire was designed it was tested, reviewed, and refined. Dunning and Martin suggest that a pilot test is the best way to ensure that the participants of a survey will find the questions appropriate and the instructions easy to understand and follow.[7] It was not possible to pilot test the questionnaire directly on adolescent patients in hospital before permission was gained, so instead, the questionnaire was reviewed by teenagers and patients outside the hospital.

To ensure that the language and layout would be clearly understood by adolescents, two 13 year-old females, a 14 year-old male and a 17 year-old male were selected to read and fill in the questionnaire. They were asked whether the questionnaire was clear and easy to use and understand, and they were invited to make suggestions on how the questionnaire could be improved. All the adolescents found the questionnaire 'easy to understand and read' with the exception of the two 13 year olds who were unfamiliar with some of the medical jargon like 'surgical wards' and 'physiotherapist'. These medical words were not changed as adolescent patients in hospital would be more likely to have some familiarity with them.

During the process of gaining approval the questionnaire was also reviewed by staff members who suggested some minor changes, and commented on the use of the 'neutral' option in the attitude scales. It was pointed out that most people prefer to see themselves as moderate and

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[6] Ford, P. and M. Walsh. *Nursing Research: Theory and Practice*. London: Chapman & Hall, p118 1994

[7] Dunning, T. and M. Martin. 'Developing a Questionnaire: Some Methodological Issues.' *Australian Journal of Advanced Nursing*. Vol 14 No2 p32 1996

often answer by ticking the middle boxes which can make the results meaningless. Edward and Talbot suggest that 'neutral' points creates a dilemma for researchers. Although some researchers think that 'neutral' tend to be overused, "others feel that a genuine mid-point response should not be denied the respondents"[8]. To address this problem the designer included the phrase "please avoid using the 'neutral' category if at all possible." The HFA Ethics Committee suggested that this was too directive, so the statement was subsequently removed.

3.2.2 the participants

The patients that the nurses identified were all aged between 12 and 20, and were physically able to fill in a questionnaire by themselves. The nurses were used to screen out patients that were too sick or distressed to be approached. While this created a bias, it should be noted that it did not affect the validity of the data, as the PIM is more likely to be used by those who are active rather than those suffering from extreme physical distress. The patients who participated were all able to speak English. This bias was unavoidable as financial and time constraints made it non-viable to supply a translator.

Patients hospitalised for mental illnesses were also excluded. Hospital management advised that their responses could be erratic and therefore difficult to analyse. It should be noted however, that although the designer was advised not to include mental health patients in the research for this study, these patients also lack resources and would benefit from the findings of this research and the resulting PIM.

It was not possible to get enough adolescent patient for the sample through the initial series of hospital visits during the interviews. It was necessary to leave questionnaires with willing hospital staff. One staff member observed that adolescents are a difficult group to get responses from. This seemed to be the case in this study with a return rate of around one questionnaire for every ten distributed. It was not until several months after the interviews that enough questionnaires were returned to begin the process of data analysis.

13 males and 17 females responded to the questionnaire. Of those 30 Patients 20 were between the ages of 13 and 17 years old (66%), 6 were between 18 and 20 years old (20%), and the youngest was 12 years old.

The participants came from a range of hospital wards. Although most participants were from Medical (11, 36%), General (7, 23%) and Surgical wards (4, 13%), there were also participants from Oncology (2, 7%), Renal (2, 7%), Respitary (1, 3%) and a Children's Ward (2, 3%) (and 1, 3%)no response).

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[8] Edwards, A. and R. Talbot. *The Hard-pressed Researcher: A Research Handbook*. London: Longman p76 1994

They were all experienced patients both in their length of stay and their number of previous admissions. Most were in hospital for over a week (17, 56%) and this included a significant number who had been in hospital for longer than a fortnight (14, 46%). Although some participants (7, 23%) had never been admitted to hospital before, most did have previous experience as patients with 50% having three or more previous admissions.

3.2.3 data analysis

The attitude scales were coded and analysed numerically to find emerging trends and patterns. Some content analysis was also required for the open-ended questions. Answers were analysed for common and important issues, coded, counted and written up under each question heading, and considered in relation to the results of the attitude scales.[9] Once the data had been analysed in relation to the questions, this information was then reorganised under the same five headings used in the literature review to allow for comparisons to be made between the survey, interviews and literature review as detailed in chapter four.

3.2.4 the questionnaire

The following 9 pages contain the patients' questionnaire. Page 38 contains the information sheet, page 39 the consent form and pages 40-46 contain the questionnaire itself.

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[9] Bogden, R. and S. Taylor. *Introduction to Qualitative Research Methods.* New York: John Wiley & Sons p83 1975

Information Sheet For Patients[1]

The Design of a Patient Information Manual

You are invited to take part in this study by answering a questionnaire about your experiences in hospital.

I am currently a design student and I have also been a patient in hospital. At present, I am gathering information that will help me design a Patient Information Manual as part of a Masters of Design Study. I am particularly interested in finding out what problems and challenges patients currently face in hospital and how patients experiences can be improved.

This questionnaire is designed to help you describe your experiences in hospital. It asks you to describe your environment, your spare time activities, your experience of other people and your feelings.

Your participation is entirely voluntary (your choice), and you do not have to answer all the questions. This questionnaire will be used to survey 50 patients. No material that could personally identify you will be used in any reports on this study. The questionnaire will be read by the researcher only and destroyed immediately after the successful completion of my Masters during 1999.

If you could complete this questionnaire it would be very useful and greatly appreciated. It will take about 20 minutes. You can either complete the questionnaire now and I will collect it, or you can return it anytime in the next 10 days in the self addressed envelope provided.

This project will be completed in the next 6 months. If you would like to be sent a summary of the results please write your address in the space provided in the consent form.

This study has recieved ethical approval from Victoria University Human Ethics Committee, the Health Funding Authority Wellington Ethics Committee and the Manager of this area has given permission for this study to be carried out.

If you have any questions or concerns, please feel free to contact me, Glenna Duthie, or you may contact my supervisor Dr Leong Yap.

In the unlikely event of a physical injury as a result of your participation in this study, you will be covered by the accident compensation legislation with its limitations. If you have any questions about ACC please feel free to ask the researcher for more information before you agree to take part in this trial.

Thank you for your time.

Yours sincerely

Glenna Duthie	Dr Leong Yap
Postgraduate Student	Supervisor, Head of Postgraduate Studies
Schools of Architecture and Design, Private Box 756	Schools of Architecture and Design, Private Box 756
WELLINGTON, Ph: (04) 475 3757	WELLINGTON, Ph: (04) 802 6245

If you have any queries or concerns regarding your rights as a participant in this research you may contact the Wellington Ethics Committee, Wellington Hospital, Ph: (04) 385 5999 ext 5185

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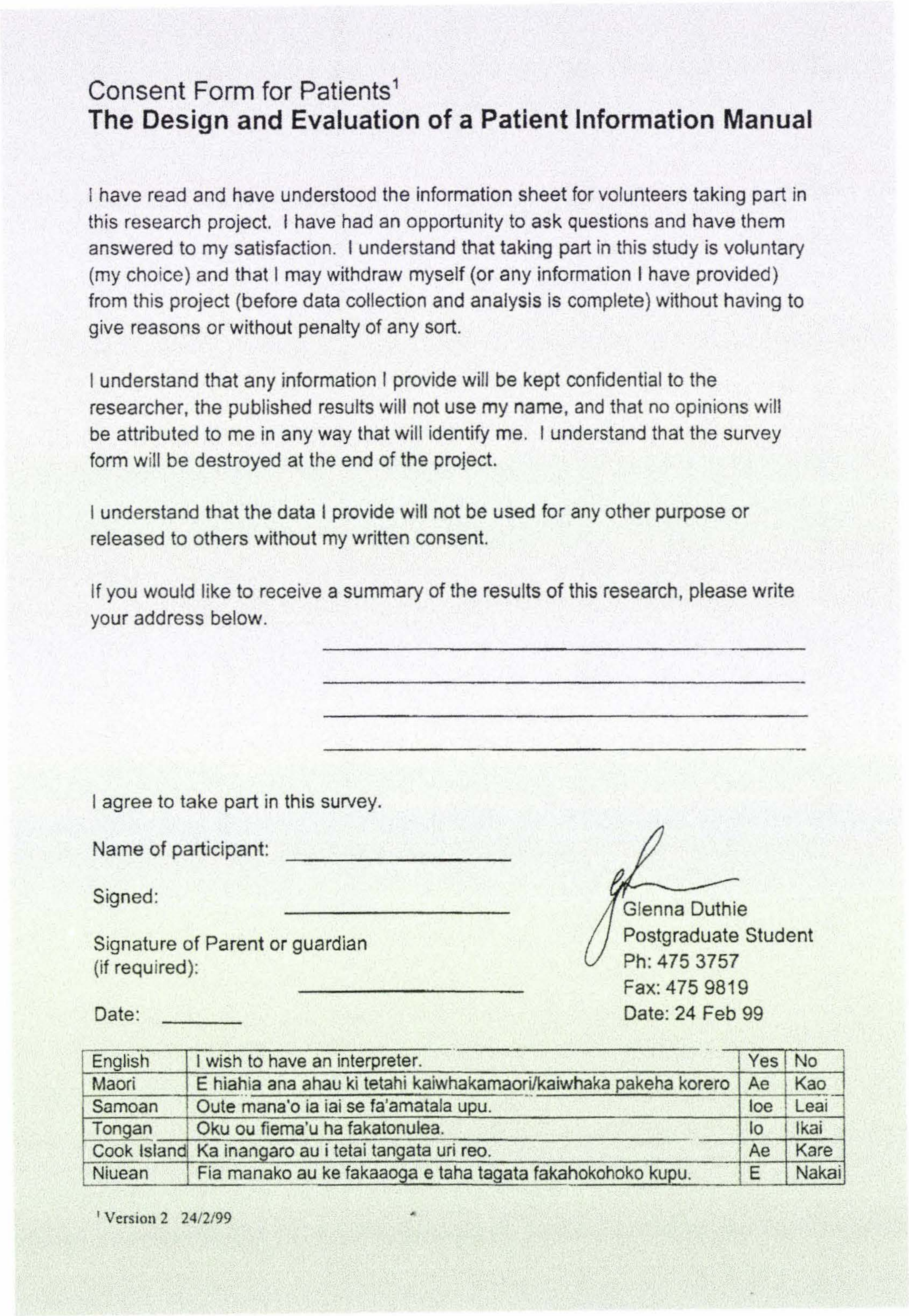
[1] Version 2 24/2/99



Consent Form for Patients[1]
The Design and Evaluation of a Patient Information Manual

I have read and have understood the information sheet for volunteers taking part in this research project. I have had an opportunity to ask questions and have them answered to my satisfaction. I understand that taking part in this study is voluntary (my choice) and that I may withdraw myself (or any information I have provided) from this project (before data collection and analysis is complete) without having to give reasons or without penalty of any sort.

I understand that any information I provide will be kept confidential to the researcher, the published results will not use my name, and that no opinions will be attributed to me in any way that will identify me. I understand that the survey form will be destroyed at the end of the project.

I understand that the data I provide will not be used for any other purpose or released to others without my written consent.

If you would like to receive a summary of the results of this research, please write your address below.

____
____
____
____

I agree to take part in this survey.

Name of participant: ________________

Signed: ________________

Signature of Parent or guardian
(if required): ________________

Date: ______

Glenna Duthie
Postgraduate Student
Ph: 475 3757
Fax: 475 9819
Date: 24 Feb 99

English	I wish to have an interpreter.	Yes	No
Maori	E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero	Ae	Kao
Samoan	Oute mana'o ia iai se fa'amatala upu.	Ioe	Leai
Tongan	Oku ou fiema'u ha fakatonulea.	Io	Ikai
Cook Island	Ka inangaro au i tetai tangata uri reo.	Ae	Kare
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu.	E	Nakai

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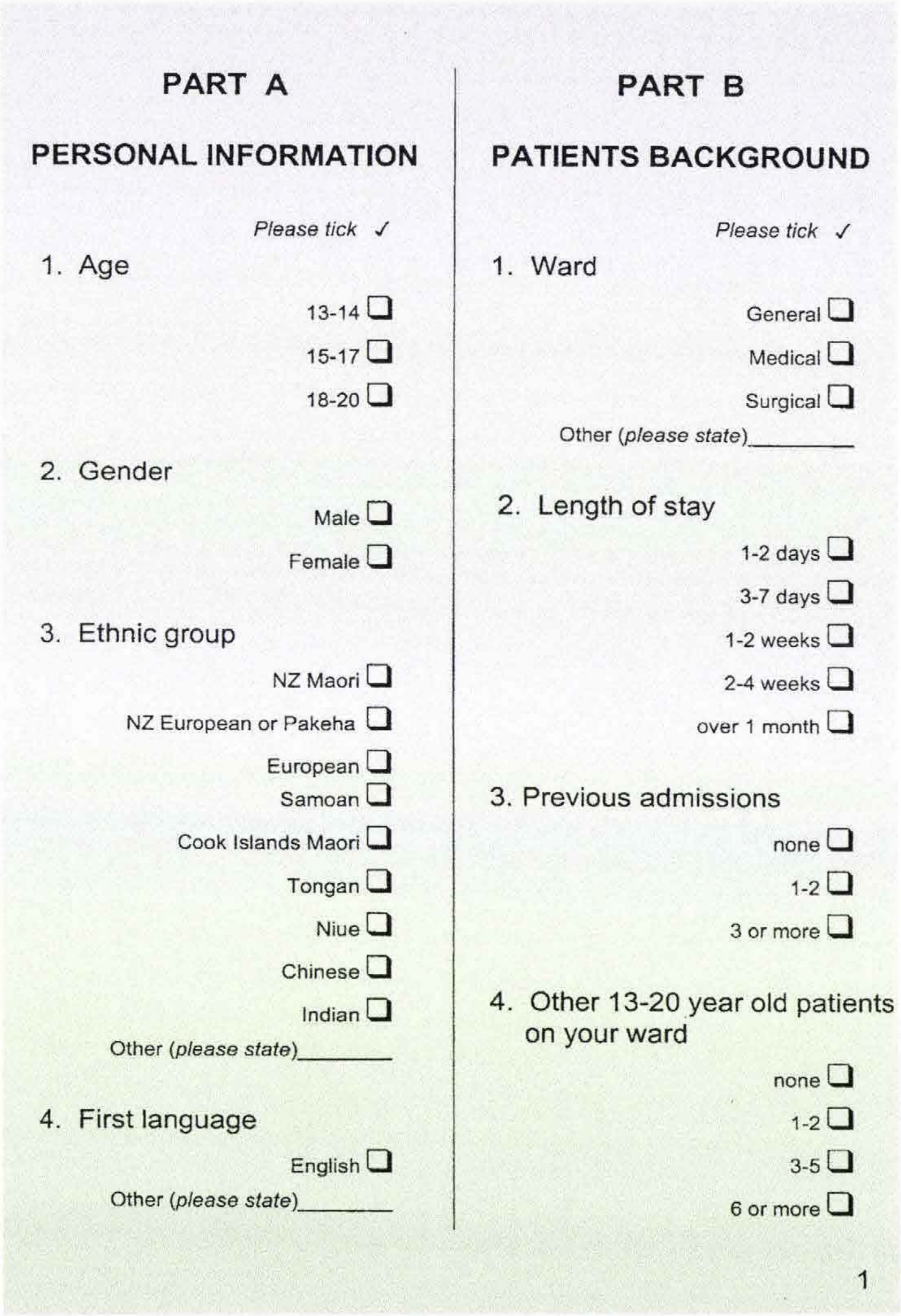
[1] Version 2 24/2/99



PART A

PERSONAL INFORMATION

Please tick ✓

1. Age

13-14 ☐
15-17 ☐
18-20 ☐

2. Gender

Male ☐
Female ☐

3. Ethnic group

NZ Maori ☐
NZ European or Pakeha ☐
European ☐
Samoan ☐
Cook Islands Maori ☐
Tongan ☐
Niue ☐
Chinese ☐
Indian ☐
Other (*please state*)________

4. First language

English ☐
Other (*please state*)________

PART B

PATIENTS BACKGROUND

Please tick ✓

1. Ward

General ☐
Medical ☐
Surgical ☐
Other (*please state*)________

2. Length of stay

1-2 days ☐
3-7 days ☐
1-2 weeks ☐
2-4 weeks ☐
over 1 month ☐

3. Previous admissions

none ☐
1-2 ☐
3 or more ☐

4. Other 13-20 year old patients on your ward

none ☐
1-2 ☐
3-5 ☐
6 or more ☐

1

PART C YOUR SURROUNDINGS

Please place a tick (✓) above the word that best describes your opinion.

1. How would you describe the surroundings from your bed?

Extremely Interesting	Very Interesting	Interesting	Indifferent	Boring	Very Boring	Extremely Boring

2. How would you describe the colour scheme on your ward?

Extremely Colourful	Very Colourful	Colourful	Neutral	Dull	Very Dull	Extremely Dull

3. If there were any pictures or images you could see from your bed how would you describe them?

Extremely Interesting	Very Interesting	Interesting	Indifferent	Boring	Very Boring	Extremely Boring

4. Please write below any suggestions you have for improving the ward surroundings.

PART D SPARE TIME

Please place a tick (✓) above the words that best describes your experience.

1. On average, how many hours of spare time did you have in a day?

0 hours	1 hour	2 hours	3 hours	4-5 hours	6-7 hours	more than 7

2. In your spare time in hospital which of the following did you do?

Please tick ✓

Listen to the radio ☐
Listen to music ☐
Read magazines ☐
Read comics ☐
Read books ☐

Watch television ☐
Play computer games ☐
Do crosswords ☐
Play card games ☐
Play board games ☐

3. Please write below, anything you did to fill in your spare time in hospital that is not mentioned above.

____

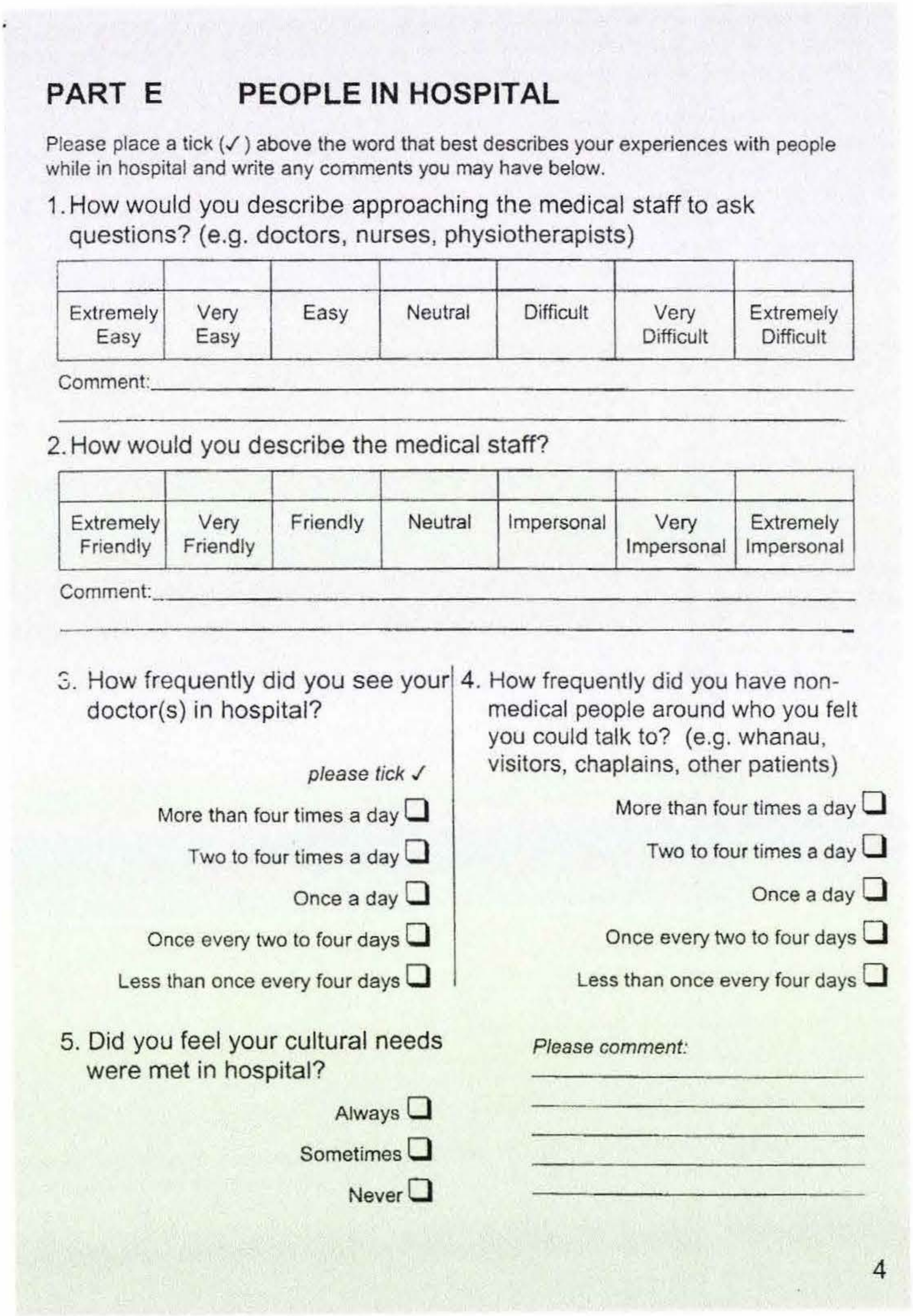
____

4. In hospital were you kept in bed because of any of the following?

Weakness ☐
Pain ☐
Splint(s) or Plastercast(s) ☐
Doctors orders ☐
Other*(please state)*__________ ☐

5. Was the use of your hands restricted by any of the following?

Weakness ☐
Pain ☐
Splint(s) or Plastercast(s) ☐
I.V. Needles or Lure(s) ☐
Other*(please state)*__________ ☐



PART E PEOPLE IN HOSPITAL

Please place a tick (✓) above the word that best describes your experiences with people while in hospital and write any comments you may have below.

1. How would you describe approaching the medical staff to ask questions? (e.g. doctors, nurses, physiotherapists)

Extremely Easy	Very Easy	Easy	Neutral	Difficult	Very Difficult	Extremely Difficult

Comment: ______________________________

____

2. How would you describe the medical staff?

Extremely Friendly	Very Friendly	Friendly	Neutral	Impersonal	Very Impersonal	Extremely Impersonal

Comment: ______________________________

____

3. How frequently did you see your doctor(s) in hospital?

please tick ✓

More than four times a day ☐

Two to four times a day ☐

Once a day ☐

Once every two to four days ☐

Less than once every four days ☐

4. How frequently did you have non-medical people around who you felt you could talk to? (e.g. whanau, visitors, chaplains, other patients)

More than four times a day ☐

Two to four times a day ☐

Once a day ☐

Once every two to four days ☐

Less than once every four days ☐

5. Did you feel your cultural needs were met in hospital?

Always ☐

Sometimes ☐

Never ☐

Please comment:

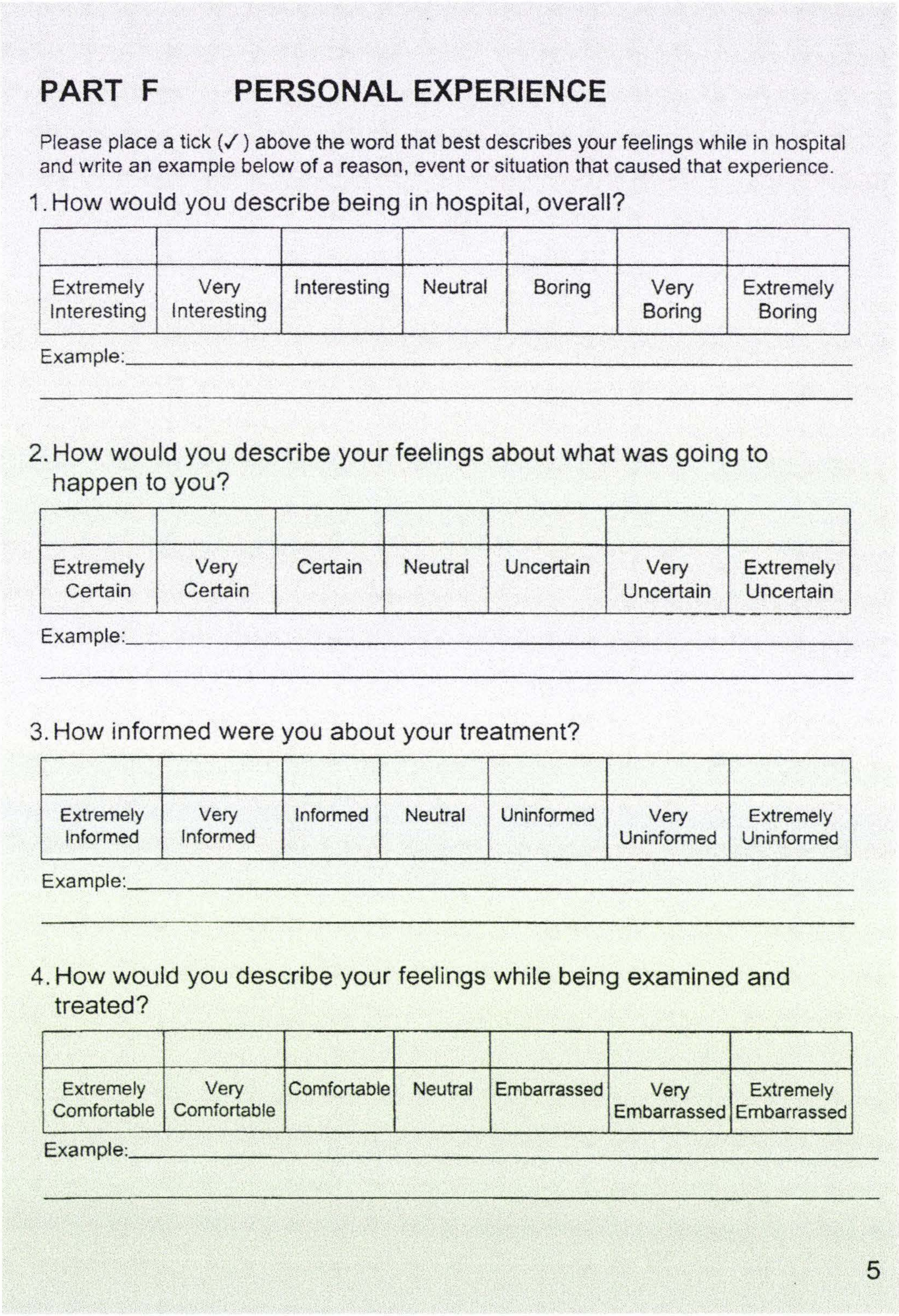
____

____

____

____

____



PART F PERSONAL EXPERIENCE

Please place a tick (✓) above the word that best describes your feelings while in hospital and write an example below of a reason, event or situation that caused that experience.

1. How would you describe being in hospital, overall?

Extremely Interesting	Very Interesting	Interesting	Neutral	Boring	Very Boring	Extremely Boring

Example:____

____

2. How would you describe your feelings about what was going to happen to you?

Extremely Certain	Very Certain	Certain	Neutral	Uncertain	Very Uncertain	Extremely Uncertain

Example:____

____

3. How informed were you about your treatment?

Extremely Informed	Very Informed	Informed	Neutral	Uninformed	Very Uninformed	Extremely Uninformed

Example:____

____

4. How would you describe your feelings while being examined and treated?

Extremely Comfortable	Very Comfortable	Comfortable	Neutral	Embarrassed	Very Embarrassed	Extremely Embarrassed

Example:____

____

PART F CONTINUED

Please place a tick (✓) above the word that best describes your feelings while in hospital and write an example below of a reason, event or situation that caused that experience.

5. How would you describe your feelings while in hospital?

Extremely Unafraid	Very Unafraid	Unafraid	Neutral	Afraid	Very Afraid	Extremely Afraid

Example:____

____

6. How would you describe your hospital experience?

Extremely Comfortable	Very Comfortable	Comfortable	Neutral	Painful	Very Painful	Extremely Painful

Example:____

____

7. Please describe below any other feelings, situations or events that you experienced while a patient, that you consider important in describing your hospital experience.

____

____

____

____

____

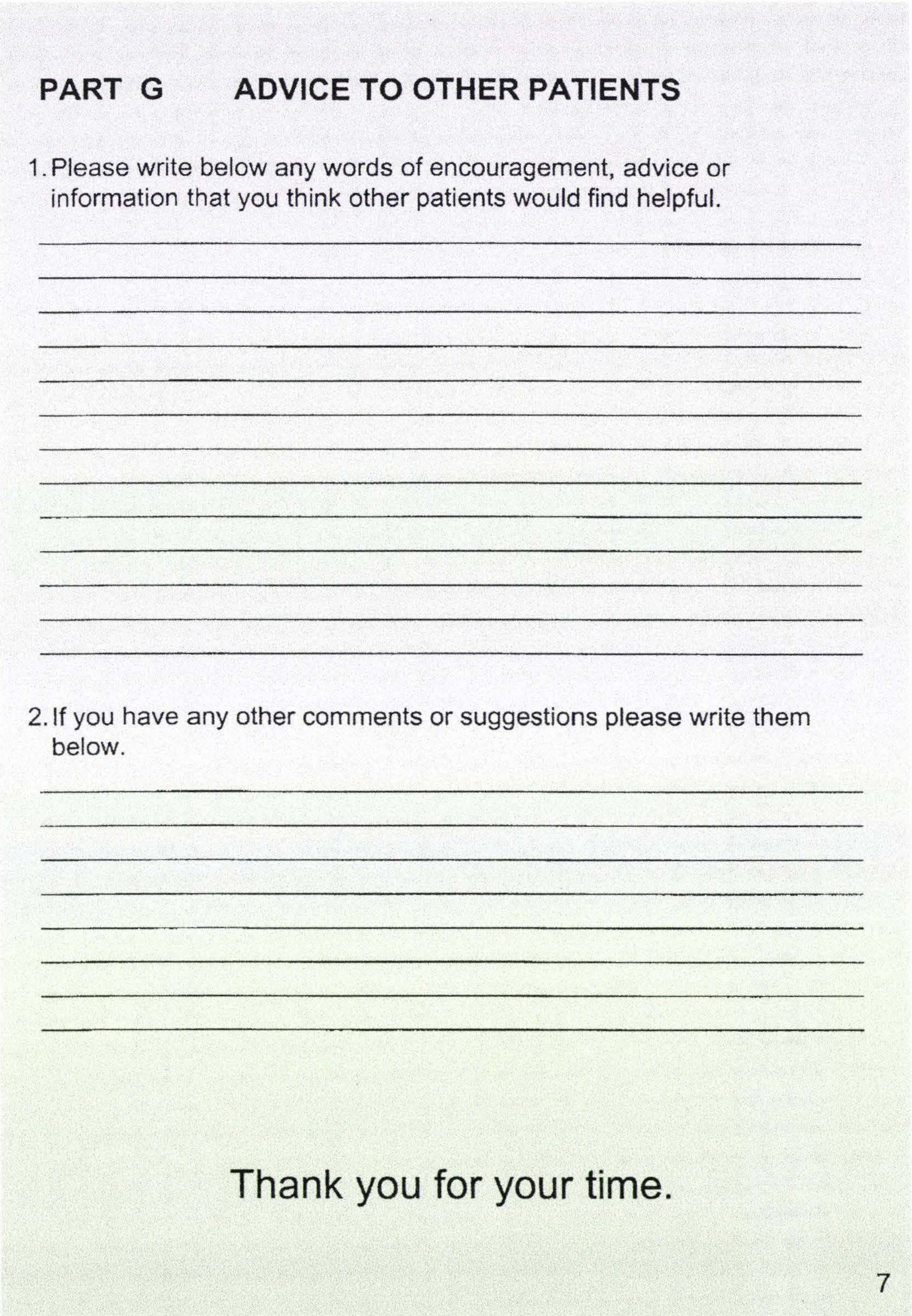
____

____

____

____

____



PART G ADVICE TO OTHER PATIENTS

1. Please write below any words of encouragement, advice or information that you think other patients would find helpful.

2. If you have any other comments or suggestions please write them below.

Thank you for your time.

3.3 staff interviews

Close liaison between the designer and the nurses, clinicians and management was necessary for a research project of this nature. The contribution of the nursing staff was particularly important for the success of the research. A semi-structured interview approach was used to allow staff to answer the questions flexibly while still allowing for a consistency in the analysis of the results[10]. Staff were interviewed to gather information about adolescent patients and patient resources to help identify which patients to include, and to facilitate the initial approaches to those patients.

Meeting the designer face-to-face enabled staff members to familiarise themselves with the project by talking directly with the designer, and allowed for more flexible questioning and dialogue to occur.

Before the interview, the designer prepared a series of open-ended questions and tested them in a trial interview with a charge nurse. From this interview it was clear that there were too many questions to address, especially as time was a restriction. The questions were edited down to the following four, which the managers and Ethics Committees subsequently reviewed and approved.

3.3.1 questions

Can you describe any problems or challenges that you have encountered in dealing with adolescent patients?

Can you describe any information, concepts or ideas that you have found successful in helping patients with any of the problems they face?

Are you aware of any publications, resources, or activities that have been designed to help patients, in particular adolescent patients, while in hospital?

Have you any suggestions of what you think would be helpful to include in a resource for adolescent patients?

3.3.2 interview process

To make the interviewees feel at ease, the interviews were constructed using the processes outlined by Morse and Field,[11] who recommend sending interviewees the questions one week in advance so they were able to prepare for the interviews and could take an active role. Staff were interviewed at a time and place of greatest convenience to them. The first few minutes of the meeting were spent in outlining the information sheet and consent form. Each participant was then provided with a copy of the questions they had been sent earlier and were asked to address these

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[10] Hardy, M. and A. Mulhall. *Nursing Research: Theory and Practice.* London: Chapman &Hall 1994

[11] Morse, J. M. and P.A. Field. *Nursing Research: The Application of Qualitative Approaches.* London: Chapman and Hall 1996

questions in their own time. Staff members were encouraged to talk freely about their personal understandings and experiences in relation to the questions. To eliminate any bias caused by selective memory the interviews were also audiotaped.[12]

Once the interview was completed staff members were thanked for their time, and asked if they would be prepared to participate in another interview at a later date to evaluate the PIM. At this point they were also asked to assist in the identifying of teenage patients to participate in the questionnaire survey.

3.3.3 participants

Recommendations from the respective management and staff of the three hospitals helped to select the staff members to be interviewed. 19 health professionals were selected and interviewed.

The participants came from a range of specialist backgrounds within the health field that included an Adolescent Health Specialist, a Doctor (special interest, adolescents), a Health Child Protection Worker/Nurse Specialist, a Social Worker (special interest, adolescents) and three Play and Recreational Specialists. Most of those interviewed however, were from the nursing staff. The eight Charge Nurses and four Nurses were from the following wards: General Medicine, General Surgery, Oncology, Orthopaedics, Renal, Respiratory, and Paediatrics.

3.3.4 data analysis

After conducting the interviews the designer transcribed the tapes. To protect the participants anonymity the names of people and places were not used. The participants were offered a copy of their transcript for their comments and amendments. The content of the transcripts was then coded and analysed to identify relevant information and useful suggestions. This information was then reorganised under the same five headings used in the final analysis of the survey findings and the literature review for the purposes of comparative analysis. These findings will be discussed in detail in the next chapter.

3.3.5 official documents

Pages 49 and 50 contain the information sheet and consent form used when interviewing the health professionals.

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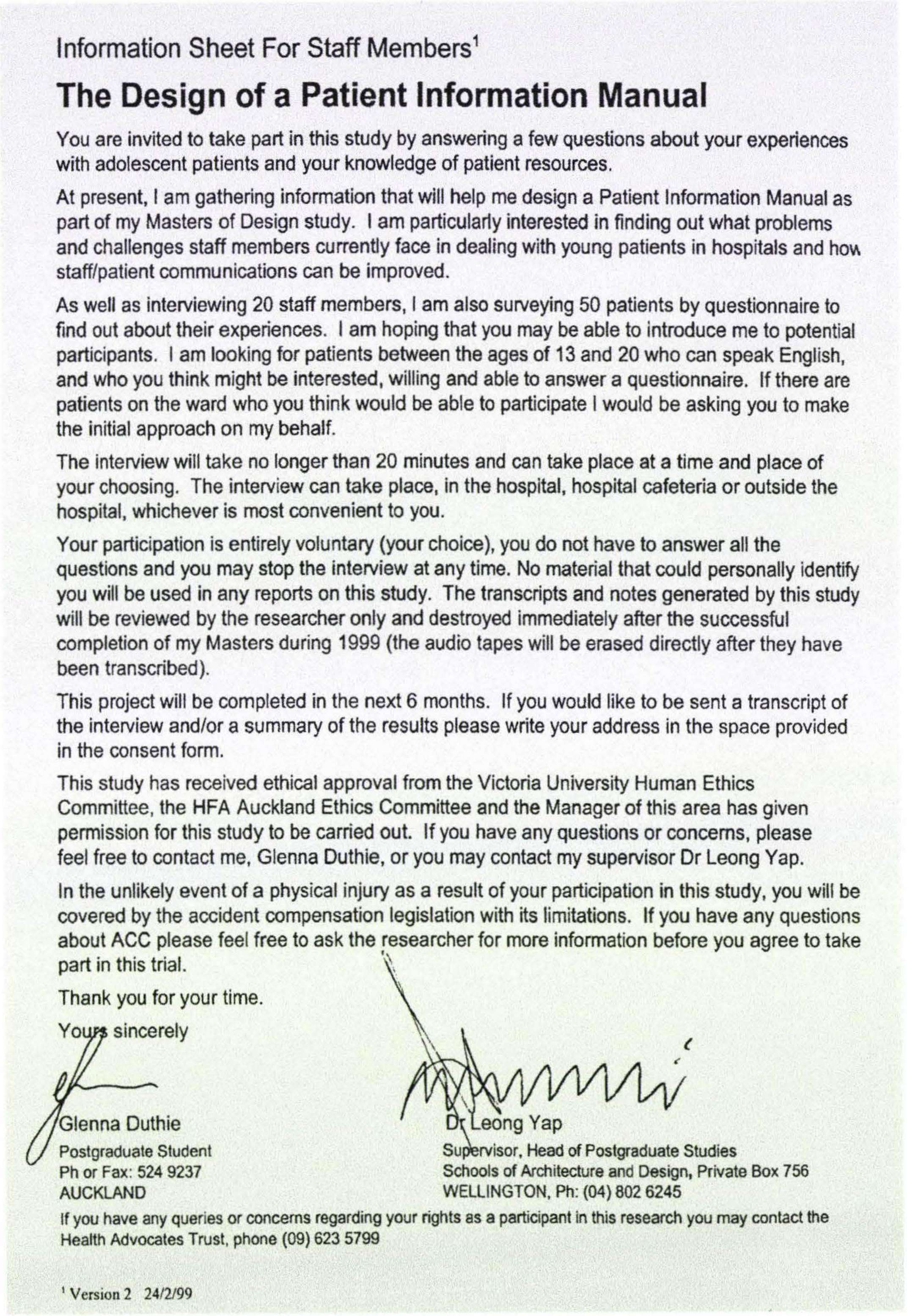
[12] Bogden, R. and S. Taylor. *Introduction to Qualitative Research Methods.* New York: John Wiley & Sons p109 1975



Information Sheet For Staff Members[1]

The Design of a Patient Information Manual

You are invited to take part in this study by answering a few questions about your experiences with adolescent patients and your knowledge of patient resources.

At present, I am gathering information that will help me design a Patient Information Manual as part of my Masters of Design study. I am particularly interested in finding out what problems and challenges staff members currently face in dealing with young patients in hospitals and how staff/patient communications can be improved.

As well as interviewing 20 staff members, I am also surveying 50 patients by questionnaire to find out about their experiences. I am hoping that you may be able to introduce me to potential participants. I am looking for patients between the ages of 13 and 20 who can speak English, and who you think might be interested, willing and able to answer a questionnaire. If there are patients on the ward who you think would be able to participate I would be asking you to make the initial approach on my behalf.

The interview will take no longer than 20 minutes and can take place at a time and place of your choosing. The interview can take place, in the hospital, hospital cafeteria or outside the hospital, whichever is most convenient to you.

Your participation is entirely voluntary (your choice), you do not have to answer all the questions and you may stop the interview at any time. No material that could personally identify you will be used in any reports on this study. The transcripts and notes generated by this study will be reviewed by the researcher only and destroyed immediately after the successful completion of my Masters during 1999 (the audio tapes will be erased directly after they have been transcribed).

This project will be completed in the next 6 months. If you would like to be sent a transcript of the interview and/or a summary of the results please write your address in the space provided in the consent form.

This study has received ethical approval from the Victoria University Human Ethics Committee, the HFA Auckland Ethics Committee and the Manager of this area has given permission for this study to be carried out. If you have any questions or concerns, please feel free to contact me, Glenna Duthie, or you may contact my supervisor Dr Leong Yap.

In the unlikely event of a physical injury as a result of your participation in this study, you will be covered by the accident compensation legislation with its limitations. If you have any questions about ACC please feel free to ask the researcher for more information before you agree to take part in this trial.

Thank you for your time.

Yours sincerely

Glenna Duthie
Postgraduate Student
Ph or Fax: 524 9237
AUCKLAND

Dr Leong Yap
Supervisor, Head of Postgraduate Studies
Schools of Architecture and Design, Private Box 756
WELLINGTON, Ph: (04) 802 6245

If you have any queries or concerns regarding your rights as a participant in this research you may contact the Health Advocates Trust, phone (09) 623 5799

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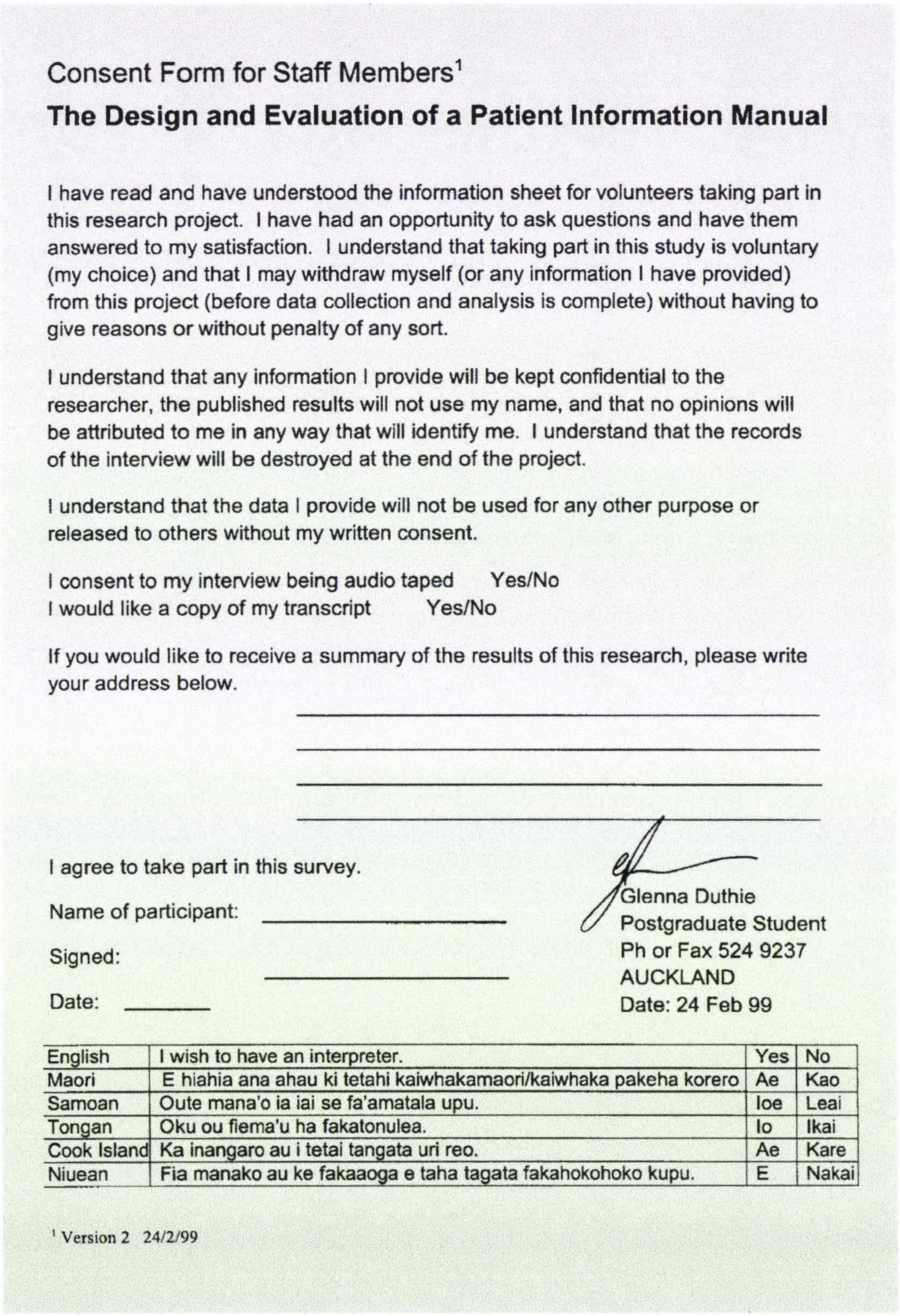
[1] Version 2 24/2/99



Consent Form for Staff Members[1]

The Design and Evaluation of a Patient Information Manual

I have read and have understood the information sheet for volunteers taking part in this research project. I have had an opportunity to ask questions and have them answered to my satisfaction. I understand that taking part in this study is voluntary (my choice) and that I may withdraw myself (or any information I have provided) from this project (before data collection and analysis is complete) without having to give reasons or without penalty of any sort.

I understand that any information I provide will be kept confidential to the researcher, the published results will not use my name, and that no opinions will be attributed to me in any way that will identify me. I understand that the records of the interview will be destroyed at the end of the project.

I understand that the data I provide will not be used for any other purpose or released to others without my written consent.

I consent to my interview being audio taped Yes/No
I would like a copy of my transcript Yes/No

If you would like to receive a summary of the results of this research, please write your address below.

____
____
____
____

I agree to take part in this survey.

Name of participant: ____________________

Signed: ____________________

Date: ________

Glenna Duthie
Postgraduate Student
Ph or Fax 524 9237
AUCKLAND
Date: 24 Feb 99

English	I wish to have an interpreter.	Yes	No
Maori	E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero	Ae	Kao
Samoan	Oute mana'o ia iai se fa'amatala upu.	Ioe	Leai
Tongan	Oku ou fiema'u ha fakatonulea.	Io	Ikai
Cook Island	Ka inangaro au i tetai tangata uri reo.	Ae	Kare
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu.	E	Nakai

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[1] Version 2 24/2/99

3.4 cultural issues

This project was also reviewed by a Maori Research Adviser for Wellington Hospital. Although this project did not target Maori specifically, Maori are over represented in patient populations. Article Two of *The Treaty of Waitangi* states that Maori shall maintain control (tino rangatiratanga) over Maori resources, including people.[13] It was therefore important to consult with a Maori representative in the health field, to ensure that the research design and content would neither cause offence nor be misinterpreted, and also to find out whether further consultation would be required.

The Maori research unit suggested the addition of the question 'did you feel your cultural needs were met in hospital? The responses to this question were analysed in relation to their ethnic group.

When the results of the questionnaire was analysed culture was not considered to be an issue for the majority of participants as New Zealand European (or Pakeha) dominated the patients sample. The participants mostly responded that their cultural needs were always meet in hospital: 'I don't have cultural needs' and 'I don't have much of a culture'. The five participants who were not New Zealand European included: a New Zealand Maori, an Armenian, a European, a South African and a Sri Lankan. Apart from the Maori and Armenian participants English was their first language. The Maori participant was the only one who felt that her cultural needs were 'never' met in hospital and suggested that she would have felt more comfortable if the nurses sometimes spoke to her in her own language.

A representative from the Maori Research Unit commented that the New Zealand European patients apparent lack of cultural concerns reflected that these patients were main stream and the hospital was therefore meeting their needs. One of the main ways in which the PIM could address the needs of other cultural groups would be through the inclusion of their language. The Maori Research Unit offered to translate some of the contents of the PIM into Maori.

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[13] Health Research Council of New Zealand. *Guidelines for Researchers on Health Research Involving Maori.* [WWW document] URL http://www.hrc.govt.nz/maoguide.htm [15/12/1998]

findings

4

The research for this project generated two sets of data that were distinct in their collection method and in their findings. The patient's questionnaire generated numerical data and written comments that expressed adolescent patients unique perspective, while the staff interviews gave the perspective of their caregivers in the form of transcripts which could be analysed.

To maintain the rich complexity of the information gathered in the interviews and questionnaire before the process of analysis, extracts from the transcripts and questionnaires have been presented in their original form (appendix page 102). Once the questionnaires and interviews were coded topically and analysed the findings were then used to develop design criteria and the content of the PIM.

To protect anonymity, the names of the patients and staff are not used. The staff titles have been abbreviated as follows: Nrs (Nurse), ChNrs (Charge Nurse), PlySp (Play Specialist), SocWrk (Social Worker), ProtWrk (Protection Worker) and AdolSp (Adolescent Specialist).

4.1 main findings

The findings from both the patient's questionnaire and staff interviews are presented using the same five factors of patient's experience used to structure the literature review. An overview of these findings are outlined below and in the matrix on the following page before they are discussed in more detail in the following chapter.

Surroundings: Adolescents found their surroundings to be dull and lacking privacy and suggested personalising their space. While staff were concerned about the lack of appropriate living space for teenagers and suggested informing them about the hospital routines.

Communications: Adolescents described staff as friendly and approachable and advised others to 'talk to staff'. While Staff found that adolescents often did not understand or ask questions and suggested informing them about staff roles.

Information: Adolescents felt afraid when they were uncertain and suggested others should stay informed. While staff noted that adolescent vary in their levels of maturity and parental involvement, but would benefit from knowing about their rights.

Activities: Adolescents were bored in hospital with plenty of spare time spent with magazines and TV. Staff on adult wards were especially aware of the lack of activities for adolescents and suggested informing them about the hospital services.

Expression: Adolescents experienced a range of feelings in hospital and advised others to be brave and strong. Staff observed that adolescents are prone to embarrassment and suggested informing them about support groups.

The matrix (fig 4.1) shows how the findings have been structured. The horizontal axis outlines the observations and suggestions from the adolescents and hospital staff. The vertical axis comprises of the subject areas used to sort the findings.

	observations		suggestions	
	adolescents find:	staff say adolescents:	adolescents advise:	staff suggest information on:
Surroundings	hospital dull privacy issue	do not fit in	bring images from home	hospital routines
Communication	staff friendly approachable	not ask or understand	talk to staff	who's who
Information	afraid when uncertain	vary in maturity	stay informed	rights and responsibilities
Activities	bored, plenty spare time	magazines and TV	bring books walkman	hospital services
Expression	sometimes feel pain	embarrassed peers problem	be brave positive	support groups

4.1 patient and staff observations and suggestions

4.1.1 surroundings

Findings from the literature review suggested that adolescent patients generally desired to be surrounded by more colour and images and that they preferred to live in more personalised spaces (page 11). In order to discover the current adolescent patients perceptions of their surroundings in hospital they were asked to indicate whether they found their environment to be 'interesting' or 'boring' (fig 4.2), 'colourful' or 'dull' (fig 4.3). They were also asked whether they found the pictures or images they saw from their bed 'interesting' or 'boring' (fig 4.4).

interesting/boring surroundings	
no response	0
extremely interesting	1
very interesting	11
interesting	4
indifferent	6
boring	7
very boring	0
extremely boring	1

fig 4.2 surroundings from bed

colourful/dull surroundings	
no response	0
extremely colourful	0
very colourful	4
colour	5
neutral	5
dull	9
very dull	4
extremely dull	3

fig4.3 colour scheme on ward

interesting/boring pictures	
no response	4
extremely interesting	1
very interesting	3
interesting	2
indifferent	7.5
boring	7
very boring	3
extremely boring	.5

fig4.4 pictures seen from bed

While adolescent patients varied in their response to these questions adolescents tended to describe the wards colour scheme as 'dull' (fig 4.3) and the images they could see from their bed as 'boring' and/or non existent (fig 4.4). Although the response to the levels of interest in their surroundings was more varied with over a third of the adolescents describing their surroundings as 'interesting'(fig 4.2).

One explanation for the range of responses to this question could be that the patients were describing a diverse cross section of wards in three separate hospitals, some of which would be designed and furnished in more interesting and colourful ways than others. When the ratings given to General, Medical, Surgical, Renal and Oncology were compared however, no pattern emerged. This would suggest that the patients were displaying a wide range of tastes by reacting in diverse ways to the same environment.

The patients' comments suggested that there were many things that could be done to make the hospital environment more suited to its adolescent population. Out of the 26 (87%) patients who commented on their surroundings, only two wrote that they liked their surroundings. 50% (15) suggested their surroundings should be less sterile and clinical, and more colourful, bright, cheerful, happy, warm, friendly, inviting or tasteful. A further 30% (10) suggested having more pictures, paintings, posters, murals or photos to look at. Two patients also suggested that they should be encouraged to bring posters and pictures from home to make them feel 'more at home'. These comments confirmed that adolescent patients generally would desire to live in a more interesting, colourful and personalised surroundings than is currently provided for them in hospital.

The staff interviews also confirmed that the hospital environment is not designed for the needs of adolescent patients. Four staff commented that the transition from children's to adult's ward was difficult and that in adult wards, staff lacked the expertise to deal with adolescents. Seven out of the seventeen staff members interviewed felt that adolescent patients often found themselves inappropriately placed with much older or much younger patients and felt that adolescents found it much harder than other age groups to be placed in ward rooms where they did not have their own personal space. One successful way of creating space for adolescents that one staff member was using was to have a graffiti board on the ward : *'I think that once you start showing that its acceptable, that there are places around here that they can use, then that's a different feeling, like being in a place were they actually belong'* (PlySp).

According to staff, the lack of space becomes an issue when adolescents wanted to entertain friends, play loud music or stay up late watching TV. Getting up in the morning was also considered to be a teenage problem: *'We have an eighteen year old who won't even talk to you till after eleven!'* (ChNrs). Some of the staff felt that an ideal solution would be to have an adolescent ward or a space in the hospital that was dedicated to adolescents (PlySp, ChNrs). Staff also suggested that the PIM could address this issue by providing information about the services that were available to adolescents in hospital, an outline of the hospital systems, timetables and expectation of each ward (ChNrs).

4.1.2 communications

Writings on staff/patient interaction in hospital have suggested that adolescents can find staff difficult to communicate with because adolescents have been found to dislike authority and can be afraid to ask questions (page 15). In order to discover how adolescent patients perceived the hospital staff, they were asked how easy they found it to ask questions of the hospital staff (fig 4.5) and whether they found them friendly or impersonal (fig 4.6).

easy/difficult approaching staff	
no response	0
extremely easy	9
very easy	5
easy	10
neutral	2
difficult	2
very difficult	0
extremely difficult	0

fig4.5 asking staff questions

friendly/impersonal staff	
no response	0
extremely friendly	10
very friendly	7.5
friendly	5.33
neutral	2.33
impersonal	1.5
very impersonal	.33
extremely impersonal	0

fig4.6 describe medical staff

Adolescent patients responses to these questions were overwhelmingly positive. 80% (24) found approaching medical staff 'easy' as opposed to 'difficult' and 30% (9) of those described staff as 'extremely easy to approach'(fig 4.5). 76% (22.83) described staff as 'friendly' as opposed to 'impersonal' with 36% (11) of adolescents describing staff as 'extremely friendly' (fig 4.6).

This positive response was also reflected in comments that described staff as excellent, approachable, kind, patient, humorous and really positive. Only 2 participants described the staff overall as 'impersonal' and 'difficult to approach'. However, five participants commented that while most of the staff were friendly there was some that were impersonal.

For many patients the 'number one' piece of advice they wanted to pass on to others related to dealing with staff members. They advised that if you want to know anything or need anything, ask the staff because the *'staff can't help you if they don't know that there is a problem'*. They also sought to reassure others that the staff are very friendly and want to help (10, 33%).

When considering the results of the questionnaire it is important to be aware that dependant populations like patients often find it very hard to be critical of their care givers and are therefore more likely to describe them positively. That tensions do exist between staff and patients in hospital was apparent in the staff interviews. While the patients generally indicated that they had no problems in communicating with the hospital staff, the staff members comments suggested that they did not find this process so easy. One staff member commented that it has been found that patients only take in a small proportion of the information that they are told, another explained that with adolescents there is the added problem of people talking to them above or below their levels of comprehension. Staff noted that adolescents often don't trust people they don't know and were reluctant to ask questions.

Nursing staff felt that patients would benefit from a clearer understanding of the roles of staff in hospital to help them address their questions to the appropriate staff member. Seven staff members suggested that a useful function for the PIM would be to help patients and staff communicate with each other by informing adolescents about who's who on the staff and encouraging them to ask questions.

4.1.3 information

Findings in the literature review in chapter two suggest that some of the problems that adolescent patients face relate to lack of information designed for them. It was also evident that informed consent was an issue with adolescents (page 18). So adolescents were asked to indicate how informed they were about their treatment (fig 4.7), how afraid they were in hospital (fig 4.8) and how certain they were about what was going to happen to them (fig 4.9).

informed/uninformed	
no response	0
extremely informed	6
very informed	9
informed	11
neutral	4
ininformed	0
very uninformed	0
extremely uninformed	0

fig4.7 feeling informed

When patients were asked about how informed they felt, their responses were also very positive. 86% (26) of the patients felt that they were 'informed' as opposed to 'uninformed' and no one described themselves as uninformed (fig 4.7). 10 participants (33%) commented positively in this section: *'the doctor was good at explaining everything.'* and *'All my questions were answered'*. However, a number of comments also suggested that the patients did not always find it easy to take on the information that they were given they included: *'I was pretty numb - it was all happening so fast'*, *'I didn't always take on what they said'*, *'I didn't like to ask questions because I didn't really want to know the answer'*, and *'Simpler words so I can understand'*.

Eight patients advised others to remain as informed as possible. *'Feel free to ask staff questions, so you feel that you are informed'*, *'Ask as many questions as possible about what's happening with your treatment'* and *'Keep as informed as possible.'*

unafraid/afraid in hospital	
no response	1
extremely unafraid	1
very unfraid	4
unafraid	6
neutral	9
afraid	7.5
very afraid	1.5
extremely afraid	0

fig 4.8 feelings of fear

certain/uncertain	
no response	2
extremely certain	2
very certain	6
certain	6
neutral	3
uncertain	8
very uncertain	0
extremely uncertain	3

fig 4.9 feeling of certainty

The importance of being informed was emphasised by the reponses to the questions on levels of fear and certainty. Patients' responses to these questions were closely related. When asked if they were afraid, 9 (30%) of the participants were 'afraid' as opposed to 'unafraid', another 9 (30%) were sitting on the fence at 'neutral' and 11 (36%) were 'unafraid' (fig 4.8). Participants responded similarly regarding how certain they felt about what was going to happen to them, with 14 (47%) patients feeling 'certain' as opposed to 'uncertain', and 10 (33%) feeling 'uncertain' (fig 4.9). When the responses on 'certainty' and 'fear' were analysed for each patient, it was found that those that were 'uncertain' were 'afraid', and those that were 'certain' were 'unafraid.' This trend was so marked that for 24 participants (80%) the degree of their fear correlated exactly with the degree of their certainty, (eg if they were 'extremely uncertain' they were also 'extremely afraid'). The only exceptions to this were four patients who had various responses to 'certainty' but were 'neutral' to the question on fear, and 2 participants who were facing operations and felt both 'afraid' and 'certain' about what was going to happen.

Those that were 'unafraid' and 'certain' commented that they were familiar with their treatments, knew what to expect, and trusted the doctors and nurses. Those that were 'afraid' and 'uncertain' spoke of facing operations, of waiting for the effects of treatment, of feeling pain, and of having ailments that *'the doctors were not really sure about'*. Two of the patients comments on their feelings of fear: *'Before being operated on I was quite afraid. Most of the time I wished I wasn't there'* and *'it made me contemplate my mortality. However after the initial shock I always knew I would survive, and my worst fear was needles'*. One patient commented that her fear closely related to how sick she felt, and to how informed she was.

Although it is unavoidable that there will be some uncertainty relating to the outcomes of ailments, treatments and procedures, helping patients to stay informed can alleviate some of those uncertainties and reduce feelings of fear.

Several staff noted that useful information already existed to help patients with specific treatments and conditions in the form of pamphlets and booklets. As each patient's condition and treatment are unique the information they were given would need to be up-to-date, accurate and specific to their individual needs. Staff talked of the 'ideal scenario' where they would tailor the available information to the individual patient's treatment plan, developmental needs, and their coping strategies (ChNrs, PlySp, PlySp). They described how useful it would be to have a packaging concept that could contain a variety of information in a flexible way that they could hand pick for each patient. *'The ideal is that everyone has their own little package of things'* (ChNrs).

The biggest complaint that staff made about existing resources related to their use of illustrations. They felt that the resources were out of date and inappropriately used a 'cartoony' style or animal themes which would no longer appeal to young people (AdolSp, PlySp, Nrs). One staff member described an illustrated information sheet that had been in use in hospital that was inappropriate and misleading. Their description of the illustration was as follows: *'the illustrations are horrendous, one is a bug, a streptococcal bug with its finger in one ear and coming out the other ear, with big feet that looks like something out of a horror movie, which is actually quite off-putting and frightening especially for adolescents who interpret things so vividly'* (Nrs).

It was discovered during the staff interviews that one of the main concerns that staff face was negotiating the sensitive issues surroundings parental support. Staff stated that communication with adolescents was complicated by parental involvement. Both informed consent and privacy were potentially fraught issues for this age group as changes in their maturity and legal status required for varying levels of parental involvement and support. Some staff observed that adolescent patients were not familiar with, but would benefit from knowing, about their rights. One play therapist commented that 'it would be great' for adolescent patients to know their rights but that this would need to be tempered with reality. The suggestion was made that the issues of privacy and patients rights be addressed in the PIM.

Staff observed that adolescents were not always well informed about their condition/treatment on their discharge from hospital. It was noted that patients were being discharged as soon as possible and were sent home to recuperate and were often back in schools with very difficult conditions (like body braces). Several staff members pointed out that it is not always possible or desirable for them to tailor-make the information for each patient and that patients should be able to choose information for themselves. Although the children's wards in hospital often have staff members (like school teachers and play specialists) who would be able to tailor packages to each patients needs, in most wards in the hospital there is no-one who can fulfil that role (AdolSp, PlySp). As two nurses pointed out: *'We use the play specialists to actually implement them - we don't have time as nurses to do it and they're excellent'* (Nrs) *'They expect a staff member to be there to interact and we actually can't supply a registered nurse for that all the time'* (ChNrs). A few of the staff felt that it would be more desirable to give patients a wider range of information for them to choose from (ChNrs). As one Play Specialist said: *'You know it's very easy for you to gate keep and to make unconscious decisions about what you think they need to know'* (PlySp).

These findings would suggest that adolescent patients do consider it important to be informed. Findings from the interviews suggest that staff are aware of the lack of appropriate and well designed information for this age group and suggested that the PIM should contain information on patients rights and informed consent, designed in a form that could work alongside existing information and that could be tailored to each patients individual needs.

4.1.4 activities

The literature suggested that the problem of adolescent boredom could best be addressed by supplying patients with puzzles and recreational/creative activities (page 26). In order to determine the extent of the need for activities and games and what sort of activities would be most appropriate patients were asked how much spare time they had (fig 4.10), the activities they participated in during their hospital stay (fig 4.11), their feelings of boredom (fig 4.12) and what restrictions they experienced in their movements (fig 4.13 and 4.14).

hours of spare time	
no response	0
no hours	0
one hour	0
two hours	1
three hours	1
four to five hours	3
six to seven hours	7
more than seven hours	18

fig 4.10 amount of spare time

When asked about their spare time in hospital, 25 patients (83%) indicated that they had more than 6 hours of spare time in a day (fig 4.10). This spare time was mostly spent in a range of recreational activities. The most popular activities were: reading magazines (27, 90%), watching Television (26, 86%), reading books

spare time activities	
no response	0
read magazines	27
watch television	26
listen to music	15
read books	15
talk to people	13
play computer games	11
listen to the radio	8
do crosswords	7
play card games	6

fig 4.11 activities in hospital

interesting/boring in hospital	
no response	0
extremely interesting	2
very interesting	3
interesting	5
neutral	5
boring	10
very boring	3
extremely boring	2

fig 4.12 feelings of boredom

(15, 50%), listening to music (15, 50%), talking to visitors, friends and nurses (13, 43%), and playing computer games (11, 36%). Patients also described periods of inactivity and on average rated their hospital stay as 'boring' rather than 'interesting' (fig 4.11). Some patients (6, 20%) commented that they found it boring because they felt there was nothing around for them to do. Their comments included: *'Nothing on TV, been reading too much, what else can I do when there is no-one here?'* and *'Just wandering around in a wheelchair trying to find something to do'*. Other patients (6, 20%) stated that they found it boring because they felt tired or sick. As most patients occupied themselves with solitary activities in their spare time and many patients were bored, the PIM needs to contain activities that would interest and engage the solitary patient over a period of time.

In order to establish ergonomic parameters for designing the PIM patients were asked if they experienced restrictions to the use of their hands (fig 4.13) and if they were bed bound while in hospital (fig 4.14).

hand movement restrictions	
no response	8
no	3
I.V. needles or lure(s)	18
weakness	3
pain	2
splint(s) or plastercast(s)	1
other	0

fig 4.13 hands restricted

kept in bed	
no response	3
no	3
pain	15
weakness	12
doctors orders	10
splint(s) or plastercast(s)	4
other (chest drain, surgery)	3

fig 4.14 bed bound

Most participants did experience some restrictions of their movements. 60% (18) of patients said that I.V. treatment restricted the use of their hands (fig 4.13), while 80% (26) were bed .bound. The most commonly stated reason for being confined to bed was pain (15, 50%) and weakness (12, 40%). Other reasons included splints or plastercasts, doctors orders, chest drain, elevated leg and I.V. treatments (fig 4.14). In regard to these restrictions to the patients' movements the PIM would have to be designed to be opened and displayed on a hospital bedside table, viewed and accessed from patients lying in their beds and be easy to manipulate without the full use of both hands.

During the interviews staff members confirmed that boredom was a notable problem when dealing with adolescent patients (eight staff members). Staff commented on the lack of resources available (on some adult wards there was only magazines) and suggested that some of the existing resources were not appropriate for this age group. It was noted that the colouring-in books that were sometimes offered to adolescent patients were designed for much younger children, and that these patients would benefit far more from drawing their own pictures than colouring in someone else's (Nrs, PlySp).

4.1.5 expression

The literature indicated that adolescent patients can experience difficulties with their feelings and emotions in hospital because of their more intense emotional cycles and lack of peer support (page 29). To determine adolescent patients need for support in hospital they were asked about the frequency of visitors (fig 4.15) and about their feelings particularly in relation to pain (fig 4.16) and embarrassment (fig 1.47).

In the questionnaire patients indicated that they were not alone in hospital. 70% (21) of participants felt that, more than once a day, they had non medical people around who they could talk to (fig 4.15) and 23 (76%) patient responses indicating that there were other adolescents on their ward while they were in hospital. However, two patients did commented on how lonely they felt ,especially with no one their own age around. Comments ranged from *'I had an extreme flow of visitors which I could talk to'*, to *'Sometimes I felt lonely and trapped'*. Two patients expressed their appreciation of the support they received from friends and family, while one patient suggested that *'for serious illness or injury, get them in touch with someone who has been through the ordeal'*. Therefore to help ensure that adolescent patients do not feel isolated the PIM should be designed to form a link with other adolescent patients' and their experiences. This could be done by providing them with stories and information from other patients their age.

frequency of non-medical visits	
no response	0
more than four a day	5
two to four a day	16
once a day	5
once every two to four days	3
less than once every four days	1

fig 4.15 non-medical visits

comfortable/embarrassed	
no response	0
extremely comfortable	1
very comfortable	2
comfortable	13
neutral	8
embarrassed	3
very embarrassed	1
extremely embarrassed	2

fig4.17 feeling embarrassed

comfortable/painful	
no response	0
extremely comfortable	2
very comfortable	5
comfortable	8.5
neutral	8
painful	2.5
very painful	3
extremely painful	1

fig4.18 feelings of pain

Most of the patients surveyed indicated that they felt 'comfortable' as opposed to 'embarrassing' while being examined and treated (16 patients 53%). While 6 indicated that they found it embarrassing (fig 4.17). Two patients commented that they were comfortable with 'being looked at' and being 'asked about bowel movements' because they were used to it. Those that were not comfortable commented that they did not like being seen throwing up, having to use a commode, and having a number of doctors and trainee doctors around during procedures. Two patients expressed their relief at being able to have privacy in a room by themselves. These comments would suggest that privacy is an issue for some adolescents. The PIM could provide patients with a means of reminding staff to consider their privacy for example a hospital equivalent of a 'knock before you enter' sign.

Patients' experiences of pain were identified in two sections of the questionnaire. 50% (15) of the participants stated that they were kept in bed because they were in pain while in hospital (fig 4.14 page 60) but only 21% (6.5) described their hospital experience overall as painful (fig 4.17). Adolescent patients gave no advice to other patients about dealing with pain. This would suggest that, on the whole, patient's pain in hospital was well managed. A couple of patients commented positively about the pain relief they received in hospital stating that they received pain relief when they needed it. However, one participant commented that he had been given morphine against his will which he was later told was a breach of his rights.

Staff members noted that there are various techniques that patients can learn that can help adolescents manage their pain in conjunction with the medications provided by the Doctors and Pain Specialists. (ChTchr, Nrs, PlySp). It was also suggested that adolescents would benefit from knowing more about pain management. The PIM could supply patients with information that relates to this topic. A number of patients wrote words of encouragement to help other patients in hospital. These mostly consisted of advising other patients to think positively and to consider their own emotional needs. 6 participants said that it was very important to be positive and look on the bright side of things, *'however small that might be'*. One patient passed on a statement that helped her: *'Be brave and be strong. I know you have it in you to beat this'*. However, these comments about being positive and brave were balanced by statements on the importance of rest and expressing emotions: *'Work through the healing process'*, *'Talking, laughing and crying help tremendously. Don't bottle anything up'* and *'Don't try to be to brave [...] let yourself rest when tired'*.

Staff supplied a different view of adolescents emotional needs in hospital based on observations of adolescent behaviours. Six staff described adolescent behaviour as unpredictable and difficult, while three staff commented that adolescents were no different from any other group of patients,. Adolescents were described as noisy, quiet, childish, grown up, cheeky, acting up, good, deviant and manipulative. It was also noticed that adolescents tended to act up around their peers and a couple of staff had experienced defiant behaviour where adolescents refuse to accept treatment (ChNrs, ChNrs). One staff member identified possible reasons for some of the more difficult adolescent behaviours, they included the hospital giving adolescent patients *'no sense of belonging or feeling of control'* (PlySp, SocWrk).

Staff observed that adolescent patients suffered from embarrassment and low self-esteem. Several staff described adolescents as being embarrassed about others seeing their bodies or body fluids, and being especially keen on having the curtains drawn around them and having some privacy (Nrs, Nrs, ChNrs). One charge nurse commented that adolescent patients sometimes find it particularly hard to come to terms with having limbs removed, burns and other ailments that made these adolescents different from their peers. Other issues include their developmental needs, issues relating to fertility and dealing with peers.

It was estimated that half of all the adolescent patients admitted to one of the hospitals suffered from low self esteem. It was suggested that some information relating to their developmental needs, like how to deal with peers, and some self-esteem exercises would be useful to include in the PIM (PlySp). Staff found that it was possible to modify adolescent behaviour by refraining from 'telling them what to do' and instead asking them what they wanted as a basis for negotiation (e.g. rewarding them with a single room for good behaviour) (ChNrs).

Two staff members had considered the idea of starting a adolescent newsletter, something produced by adolescents for adolescents from which patients could gain insights by sharing their problems (ChNrs, ChTchr). Staff also mentioned that they had encouraged adolescent patients to write letters to management to advocate for the provision of services designed for young people (ChNrs, PlySp). A play specialist described an exchange with an adolescent on an adult ward: *'When he saw me going up and down with resources he just called out, I said there is something you can do about this and I encouraged him to write a letter to the department just to say that this is not a place for me'* (PlySp).

Socially, financially and emotionally adolescents are a vulnerable group that are often unaware of the community/support groups and resources that are available to help them (ProtWrk, ChNrs). A number of the staff interviewed suggested that even if the information was not used immediately, informing patients of these community resources would prove to be valuable in the long term (SocWrk, ProtWrk and PlySp). *'Whether they pick it up like 6 months or 10 years down the track it doesn't matter, it's there if and when they feel they need it'* (PlySp). They suggested that the PIM could serve a useful purpose by informing adolescent patients about what organisations and community groups were available for young people.

4.2 summary

Although it was evident from the responses gathered in this research that each patient's and staff members experiences and needs are unique, it was possible to establish some trends that could be used to determine the messages and information that the PIM needed to contain.

The messages that adolescent patients wanted to pass on to other young patients in their situation contained the following: personalise your surroundings; communicate with hospital staff; stay informed; don't bottle your emotions up; and find other people who have experienced the same thing.

During the interviews staff members mentioned the following information could be contained in the PIM : hospital routines and services; hospital staff roles and how to recognise them; patients' rights and responsibilities and the privacy act; and how to contact support groups and support personnel

4.3 design criteria

The findings suggest that the PIM would need to be designed to fulfil a number of specific functions. The PIM needs to:

allow staff to tailor the contents to suit the specific needs of individual patients;

contain existing pamphlets/booklet, official information, messages from other adolescent patients, and information in a form that patients can take home;

display its contents within the space of a patient's bedside table;

be easy to manipulate without the full use of both hands;

fold away for easy storage

The PIM also needs to function as a conversation opener between adolescent patients and their care givers and supply patients with information, a means of self expression, activity and entertainment.

5

design & evaluation

Based on the Design Criteria and the findings of the research the designer created five different packaging concepts. These were developed and made into working prototypes (fig 5.1). Each one was designed to contain eight pamphlets and/or activities in a folded A4 format that could easily be displayed, removed and replaced. To determine which system would be most suitable for the hospital environment, these packaging systems were evaluated by hospital staff.

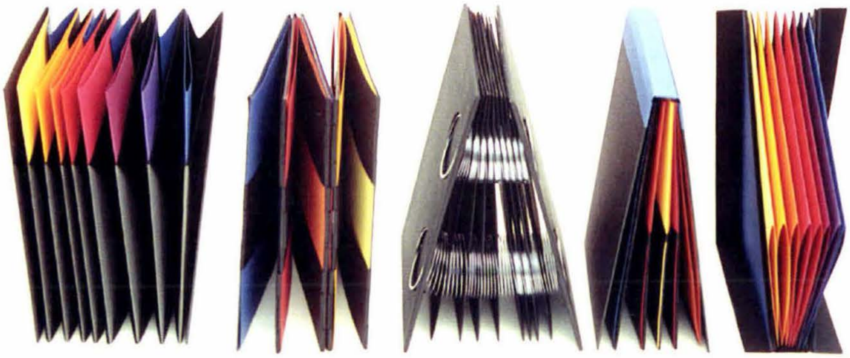
fig5.1 packaging systems

fig5.2 pamphlets & activities

The designer went on to create a series of pamphlets and activities that would convey the messages and information suggested by the adolescent patients and the hospital staff (fig 5.2). The Patient Information Manual (PIM) consists of pamphlets and activities contained in a packaging system.

The PIM was then evaluated by hospital staff and patients to gather suggestions for its improvement and to determine its appropriateness and helpfulness in aiding adolescent patients in hospital. Both of these design and evaluation processes are outlined in this chapter along with images of the finished PIM.

5.1 five packaging systems



fan concertina magic book slinky spring zig zag triangle box

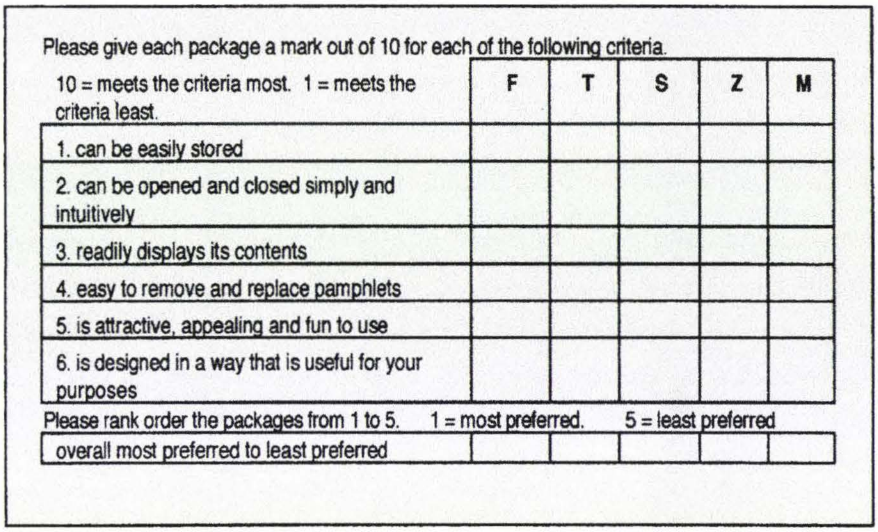
fig5.3 a side view of the packaging systems

5.1.1 evaluation process

Four hospital staff and a designer were chosen to evaluate these packaging systems and to choose which system would work best in hospitals. They included a nurse (Nrs), a nurse educator (NrsEd), two hospital children's teachers (ChTchr) and a designer (Dsnr).

For this evaluation each system was labelled: Fan concertina (F); Triangle box (T); Slinky spring (S); Zig zag (Z); and Magic book (M).

The evaluators were asked to grade each system from one to ten for each criteria and rank each system in their order of preference, using the following form:



Please give each package a mark out of 10 for each of the following criteria.

10 = meets the criteria most. 1 = meets the criteria least.	F	T	S	Z	M
1. can be easily stored					
2. can be opened and closed simply and intuitively					
3. readily displays its contents					
4. easy to remove and replace pamphlets					
5. is attractive, appealing and fun to use					
6. is designed in a way that is useful for your purposes					

Please rank order the packages from 1 to 5. 1 = most preferred. 5 = least preferred

overall most preferred to least preferred					

fig5.4 the packaging systems evaluation form

The designer explained the purpose of the packages to the evaluators and talked them through the criteria on the evaluation sheets. To enable the designer to observe how people opened and explored the packages without prior knowledge or guidance, the designer did not present the systems to the evaluators but placed them on the table and encouraged the evaluators to open and play with the packages themselves. During this process the designer noted the verbal comments made by the evaluators and made observations about how they handled each systems.

The results of the evaluation forms were then tabulated, averaged, and analysed for emerging trends and areas where there were differing opinions. The average scores that each system gained, when evaluated against the criteria, were also compared with their rank order.

Each packaging system is introduced in turn with a description of its concept and design, how it faired in the evaluation, and comments made about it. All five systems are then compared to confirm which packaging system to use as the basis for further development.

5.1.2 fan concertina

All five concepts are based on the most commonly used method of storing and receiving information - the book. Whereas a standard book is designed to be opened in only one way, from right to left, this package was designed to be opened in any direction. The designer aimed to give the audience a different experience depending on the direction in which the system was opened.

fig 5.5 coloured pamphlets in fan concertina

As the designer explored different construction methods the book transformed into a concertina. This concertina construction had a number of unanticipated benefits. As well as being able to open in any direction it was also possible to display the system in a variety of ways. The standard rectangular shape of a stored book could be expanded into a wide box (fig 5.6) and displayed as a carousel (fig 5.7) or fan (fig 5.8) while still containing and displaying its contents.

the fan concertina displayed in different ways

fig 5.6 expanded

fig 5.7 carousel

fig 5.8 fan

evaluation

The Fan Concertina received positive response when scored against the criteria, scoring 273 out of 300 (91%). It was also ranked favourably.

	design criteria							
	1	2	3	4	5	6	totals	rank
nurse	10	10	10	8	10	10	58	2nd
hospital teacher	10	6	10	7	9	8	50	4th
nurse educator	10	10	8	7	10	10	55	2nd
hospital teacher	10	10	9	8	9	8	54	2nd
designer	10	9	8	10	9	10	56	2nd
totals	50	45	45	40	47	46	273	2nd

fig 5.7 fan concertina scores

When the evaluators considered how easy it was to open and close, (criteria 2) they all gave the Fan Concertina high scores, (9's or 10's) except for one evaluator who gave the system a relatively low mark, 6 (NrsEd). This evaluator tried to open the package with one hand to see how easy it might be for patients who may be restricted in the use of their hands by lures or plaster. She discovered that it was rather bulky and potentially 'difficult to manage' with one hand and felt that it would be easier if it did not come in a box.

This lowest scores for criteria were gained for 'ease of removing and replacing pamphlets'. The scores for this criterion ranged from 7 to 10 (criteria 4). The designer observed that this range related to the way different people displayed the system when putting in and taking out the pamphlets. When the Fan Concertina was expanded (fig 5.6) it was extremely easy to work with the pamphlets and the system was rated significantly better with an average of 8 for this criteria. When it was formed in a fan (fig 5.8) or carousel (fig 5.7) it was slightly harder to use and received comparatively lower scores.

Two participants commented that it did not reveal much of the pamphlets (NrsEd, Dsnr) and another commented that the interior shapes created by the construction were distracting and could be confusing, but that this could be remedied if the exterior structure was used to carry some of the content (Dsnr). However all the evaluators expressed their enjoyment of Fan Concertina and spent some time manipulating it.

5.1.3 triangle box

This design began with an exploration of the simple rectangular box. The designer experimented by slicing a rectangular box vertically, horizontally and diagonally from each of its six sides and hinging the severed sides back together in various ways until an interesting and practical solution emerged.

fig 5.8 the triangle box

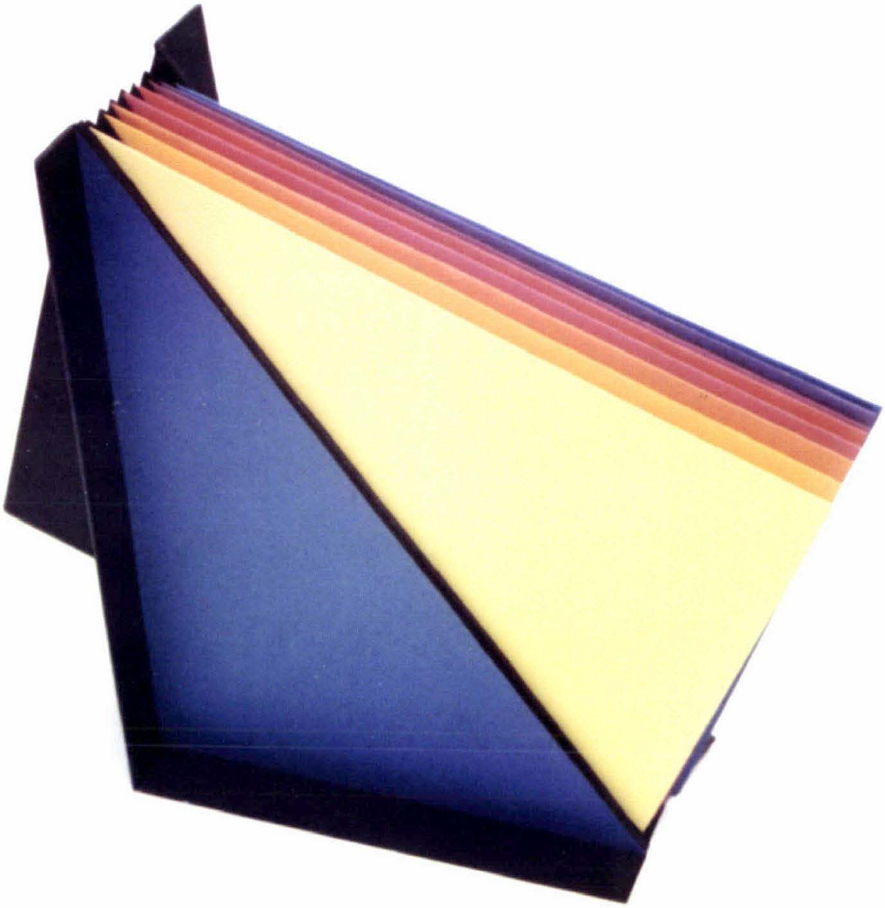


fig5.9 triangle box standing on its cover

In this concept the book cover becomes its own storage box. The diagonal hinges through the front and back covers help to expose the contents and if the box is leaned back these flaps becomes its own stand or lectern (fig 5.9). By also making the storage pages diagonal, each pamphlet has maximum exposure and was easy to remove (fig 5.11).

fig5.10 triangle box open

fig5.11 removing the pamphlets

evaluation

The Triangle Box also rated highly with participants, scoring 283 out of 300 (94%). While all the criteria consistently gained high scores this system did lose some points on 'how easily it could be opened' (criteria 2), on 'how effectively it displayed its contents' (criteria 3), and on 'how useful it was'(criteria 6) Scoring 48 out of 50 for these criteria.

	design criteria							
	1	2	3	4	5	6	totals	rank
nurse	8	7	10	10	10	8	53	3rd
hospital teacher	10	10	8	10	10	10	58	2nd
nurse educator	10	10	10	10	10	10	60	3rd
hospital teacher	10	10	9	9	10	9	57	3rd
designer	10	9	9	10	8	9	55	3rd
totals	48	46	46	49	48	46	283	3rd

fig 5.12 triangle box scores

Three evaluators gave an 8 and 9 for its ability to display its contents as it was not obvious that when leaned backwards it could display itself (criteria 3). The lowest score given by one participant was 'for ease of opening' (Nrs) (criteria 2). While most of the evaluators found it very easy to open, this evaluator found that when she tried to open it with one hand when the system was lying flat on a table the cover flapped back awkwardly and from this position it was a little more difficult to access the pamphlets. One evaluator commented that if the envelopes were made smaller in relation to the box, it would solve the problem of accessing the contents with one hand when the system was lying flat (fig 5.13). The evaluator suggested that rounding the corners of the hinging part of the box would improve the design. This evaluator also expressed a feeling of surprise at the 'unexpected' and interesting way that the Triangle Box opened (Dsnr).

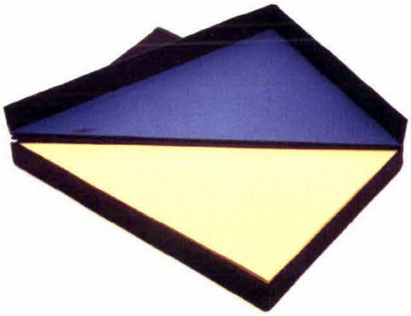


fig 5.13 triangle box lying flat

5.1.4 slinky spring

To engage adolescent patients' interest in the PIM the packaging system needed to be fun to use. To fulfil this function, the designer set out to incorporate a 'slinky' spring as part of the packaging design. The first prototype used one spring as part of the binding. This design required minimal manipulation for successive views of the pamphlet titles as the spring amplified small hand movements.

fig 5.14 the slinky spring

However, this design was unstable when closed. In the second prototype this problem was solved by using two springs to give more stability and strength to the design. This design was proved to be successful in holding the system together which gave the whole design a greater elegance and flexibility. It was now able to be opened from the side of the spine and to be suspended from its cover (fig 5.15).

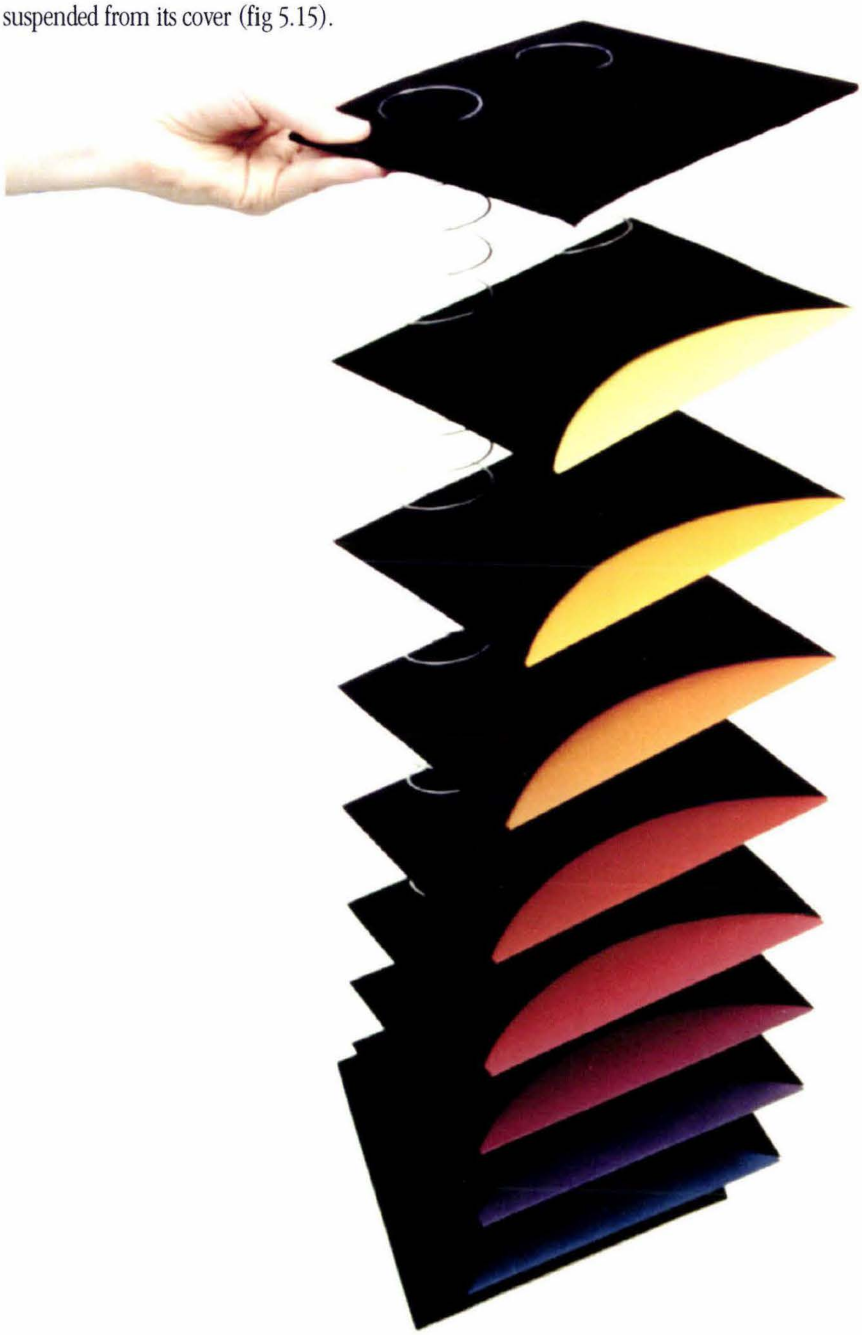


fig 5.15 slinky spring suspended from cover

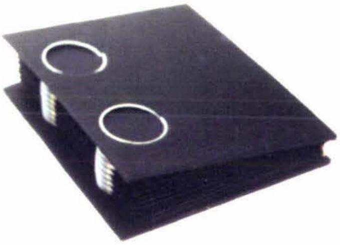
evaluation

Slinky Spring was extremely successful when scored against the criteria, with an overall score of 296 out of 300 (98%). It received 10 out of 10 for ease of opening, usefulness, attraction, appeal and the fun factor.

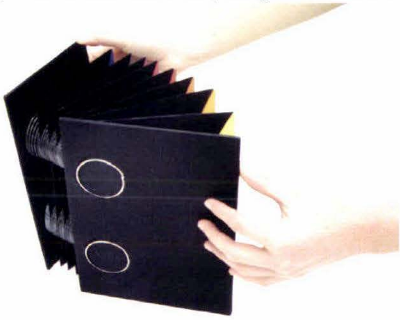
	design criteria							
	1	2	3	4	5	6	totals	rank
nurse	10	10	10	9	10	10	59	1st
hospital teacher	10	10	10	10	10	10	60	1st
nurse educator	10	10	10	10	10	10	60	1st
hospital teacher	10	10	10	10	10	10	60	1st
designer	9	10	10	9	10	10	58	1st
totals	49	50	50	48	50	50	297	1st

fig 5.16 slinky spring scores

There were only two criteria in which this design did not receive an overall perfect score. They were 'ease of storage' (9.4 out of 10, criteria 1) and 'ease of removing and replacing the pamphlets' (9.6 out of 10, criteria 4). This system was considered slightly more difficult to store because when closed it was considerably higher on the side of the springs making it slightly bulkier and less evenly shaped than other designs (Nrs) (fig 5.17).



5.17 slinky spring closed



5.18 slinky spring opened

Although the pamphlets are very easy to pull out they could be 'fiddly' to put back in, especially with one hand (fig 5.19). One evaluator commented that this could be remedied by changing the shape of the envelopes (Dsnr).

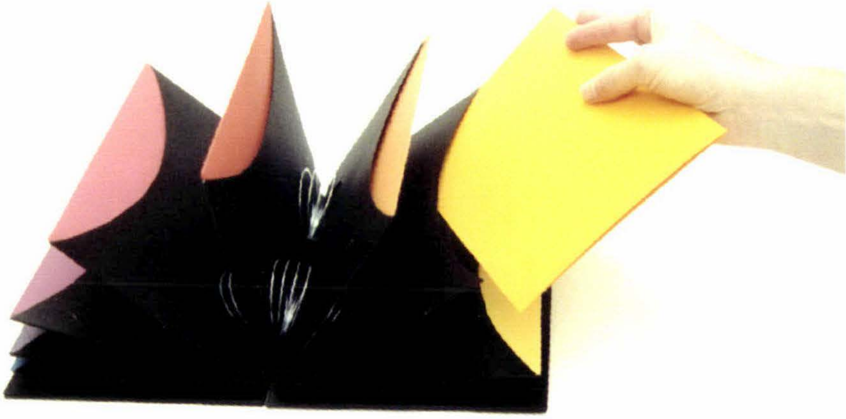


fig 5.19 replacing the pamphlets

This design received an overwhelming and immediate positive response. All the evaluators wanted to interact with this system and spent some time with it, and loved it. During one of the evaluations a young patient selected the Slinky Spring to play with from among the other designs, because of its originality and playfulness.

5.1.5 zig zag

This design was generated by using a chain of envelopes folded away in a simple zigzag. Experimentation led to the use of a diagonal design in which each pamphlet was contained in its own envelope. When displayed on a table this design could be stretched very wide and created an expanded landscape format.

fig 5.20 removing pamphlets from the zig zag

evaluation

When considered against the criteria this system faired poorly, scoring 190 of 300 (63%). Although it was awarded a 10 for 'ease of storage' (criteria 1) it received the lowest scores for all the other criteria. This system was created to stand upright on a table, to be opened and closed, and to make it easy to remove and replace the pamphlets from a vertical position. The evaluators intuitively tried to open and explore the contents when the system was lying down which brought to light several design issues that would need to be

	design criteria							
	1	2	3	4	5	6	totals	rank
nurse	10	6	5	6	6	6	39	5th
hospital teacher	10	7	6	6	6	6	41	5th
nurse educator	10	5	7	6	6	4	38	5th
hospital teacher	10	6	4	4	8	7	39	5th
designer	10	6	5	3	4	5	33	5th
totals	50	30	27	25	30	28	190	5th

fig 5.21 zig zag scores

addressed. The evaluator's first instinct was to try to open it from the bottom. From this position however, the pamphlets could not be readily accessed, which accounted for its low ratings for ease of opening (30 out of 50, criteria 2). From this horizontal position two of the pamphlets threaten to fall out. This angle also made it harder to insert the pamphlets so it was given a low rating for 'ease of removing and replacing pamphlets' (25 out of 50, criteria 4). These factors influenced the evaluator's impressions of how readily it displayed its contents and how appealing or fun it was to use (30 out of 50, criteria 5). One evaluator commented that 'Zigzag did not really work' (Nrs), another said that it was easy to open but 'not intuitive'.

5.1.6 magic book

When brainstorming for alternatives to the traditional book the idea of a 'Magic Book' emerged. The designer was aware of two existing uses of the magic book construction. One was a children's toy of wooden blocks, cleverly bound together by two ribbons that hinged and folded out in unbelievable ways. The other was a paper book divided into thirds that would hide half the story at any given time depending on which way it was opened. The designer explored the idiosyncrasies of the figure of eight device that created the 'magic'.

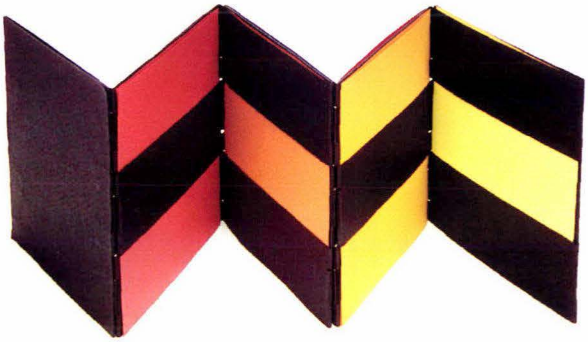


fig 5.21 the magic book expanded

Each page is hinged to the next from both sides, so at each point the decision must be made as to whether to open the system from right to left or left to right. This system can be read like a book from cover to cover (fig 5.22) or it can be folded out into a long rectangle (fig 5.21). Whichever way the design is configured all the pamphlets will be seen. This design allows images and/or text to be juxtaposed in interesting and surprising ways.

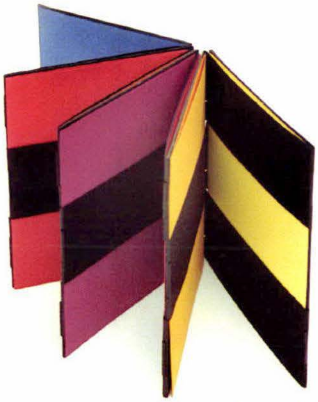


fig 5.22 magic book in book form

evaluation

The Magic Book was scored well against the criteria with a score of 236 out of 300 (79%). For ease of storage this system unanimously scored a 10 out of 10 (criteria 1) but for ease of opening, display of contents and ease of removing and replacing the pamphlets the scores were mixed.

	design criteria							
	1	2	3	4	5	6	totals	rank
nurse	10	7	6	10	7	7	47	4th
hospital teacher	10	10	9	7	8	7	51	3rd
nurse educator	10	10	8	6	7	7	48	4th
hospital teacher	10	10	6	8	8	7	49	4th
designer	10	6	6	7	6	6	41	4th
totals	50	43	35	38	36	34	236	4th

fig 5.23 magic book scores

Three evaluators found it easy to open and close and gave this system 10 out of 10; the other two experienced problems and gave the magic book a rating of 6 and 7 out of 10 (Dsnr, Nrs) (criteria 2). It was found that when the system was opened out while in a vertical position some of the pamphlets would begin to slip out (ChTchr, NrsEd). Reactions were mixed about how easy it was to remove and replace pamphlets with scores ranging from 6 to 10 out of 10 (criteria 4) (fig 5.24). Although all the pamphlets can be seen and accessed only half of them could be described as easy to take out and put in at any given time.

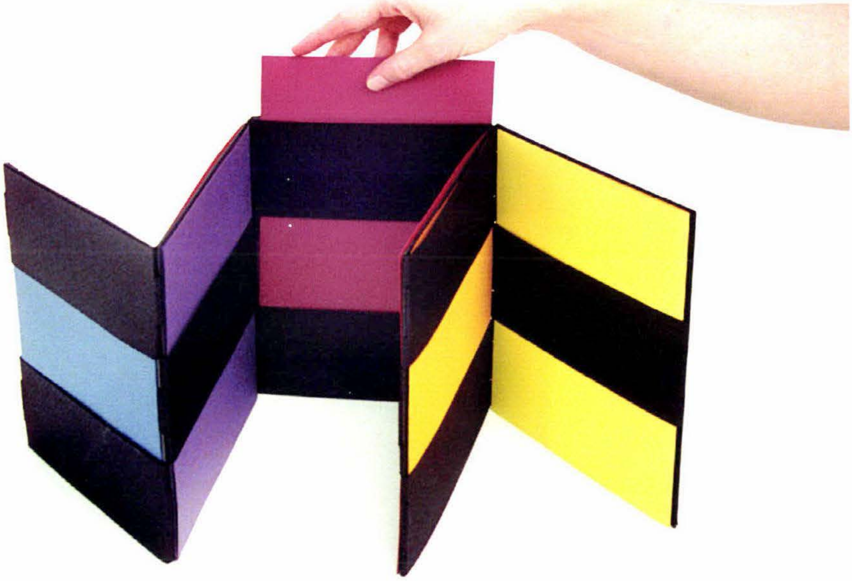


fig 5.24 removing pamphlets from the magic book

One evaluator commented that although Magic Book was not as practical as some of the other ideas, it had definite potential depending on how the graphics were designed (Dsnr).

5.1.7 five systems compared

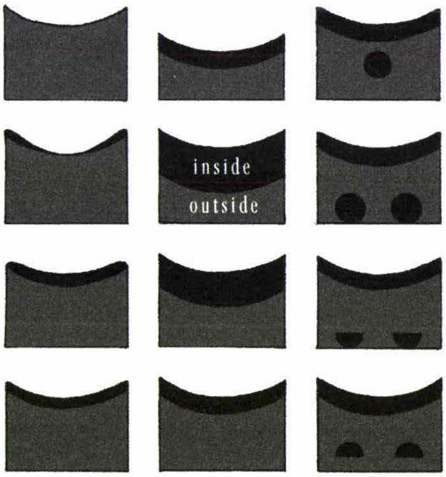
When the overall totals from the analysis were compared, the top three scored very closely, with Slinky Spring 98%, Triangle Box 94% and Fan Concertina 91%. The next favourite was Magic Book 79% and the least favourite was Zigzag 63%.

When the evaluators were asked to rank the systems in order of preference (without referring to the results of their analysis but just by their overall impression) there was a change to the order of preference. Triangle Box that had come second in the analysis was swapped with Fan Concertina that had come third in the analysis. So, although Triangle Box was slightly more practical and easy to use, overall the evaluators preferred Fan Concertina.

In line with this evaluation the Slinky Spring design was selected for further design development and evaluation. Responding to the advice from the evaluators, the shape of the envelopes in the Slinky Spring was be modified to ensure that it was easy to replace them.

5.1.8 redesign of envelopes

The original envelope shape used in the Slinky Spring consisted of a rectangle attached on three sides (page 72). On the fourth side was the opening cut in a concave shape. When a pamphlet was placed in these envelopes a small curved portion of pamphlet could still be viewed. Through experimentation it was found that it was much easier to guide the pamphlets back into the envelopes of the Slinky Spring if one side of the envelope was shorter than the other. Further experiments generated alternative proportions some of which proved to be more functional than others (fig 5.25).



5.25 envelope experiments

Various circular cuts used to accommodate the spring binding required further exploration before the final design of the prototype was determined (fig 5.26).

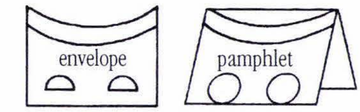
5.26 final envelope design

5.2 pamphlets and activities

The PIM consists of a packaging system and its contents of activities and pamphlets. Once the packaging system was determined, the design of the pamphlets and activities could commence.

5.2.1 the pamphlets

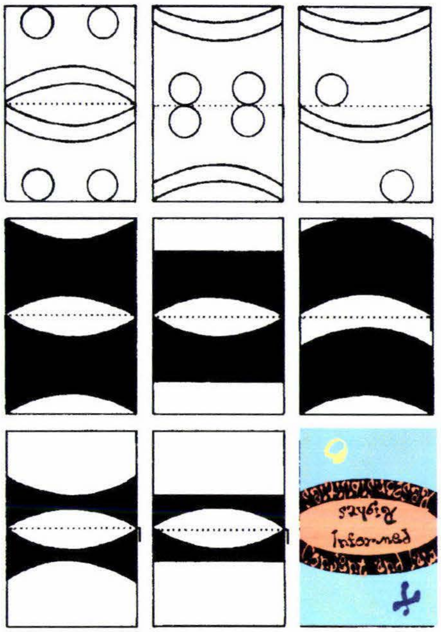
The envelopes were designed to contain A4 pamphlets folded into A5. The pamphlets had to function as labels and encourage patients and staff to explore its contents, while also fulfilling various aesthetic and practical functions. This was achieved through the use of both colour and composition.



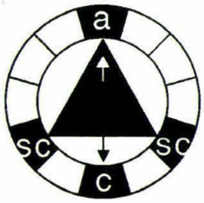
5.27 envelope and pamphlet

The pointed oval shape in the centre of the final pamphlet design has links with iconic pacific island designs while also directly relating to the curved opening of the envelopes (fig 5.27-8). An array of rainbow colours was chosen for the centre of the pamphlets so that, when all the pamphlets were installed in the dark packaging system, they created an optimistic, bright and orderly sequence of colour (fig 5.30). Each pamphlet also contained colours that could only be seen once the pamphlet was removed from its envelope.

A colour formula was developed to select the colour combinations used in the pamphlets (fig 5.29). The accent colours (that were only used for small patterns) were complementary (a and c) while the main two colours consisted of split complemetaries that formed a triangle in the colour wheel (a and sc). By moving this triangle around the sphere it was possible to generate all the colour combinations for the outside of the pamphlets (for example, the predominantly red and blue pamphlet also contained orange and purple). As discussed in the literature review (page 14) this harmonious combination of pure hues is most likely to have a wide appeal and therapeutic value for adolescent patients.



5.28 pamphlet designs



5.29 colour wheel

5.30 colour combinations of the pamphlets

Each pamphlet had a theme relating to the findings of the research. The pamphlets titles were: Rights/Informed; Private/Space; Ask/Staff; Give/Receive; Ward/Specific; Feel/Laugh; Odds/Ends and; Ouch/Pain.

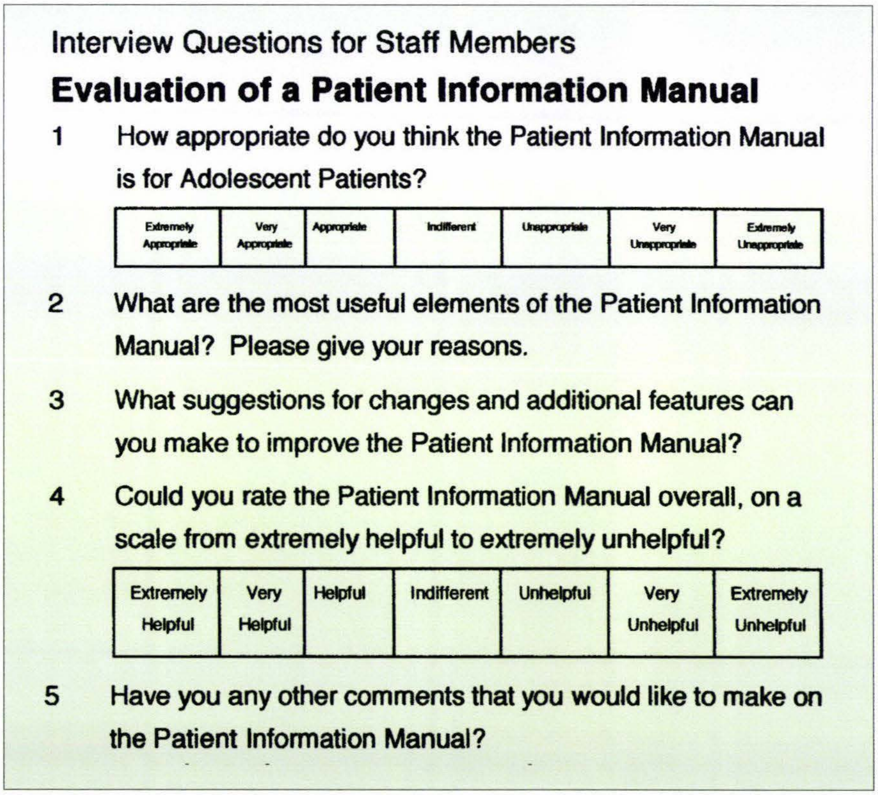
5.2.2 the activities

A series of activities were designed to fit inside the pamphlets (fig 5.31). These activities are discussed along with the pamphlets and the evaluative comments on the following pages. The activities include: Passport/Diary; A Maze; Paper Dolls; Certificates; Feeling Clock; and Word Game

fig 5.31 activities

5.2.3 evaluation process

Ten health care professionals and three adolescents participated in the evaluation of the eight pamphlets and five activities. They were asked the following questions during the evaluation:



Interview Questions for Staff Members

Evaluation of a Patient Information Manual

1 How appropriate do you think the Patient Information Manual is for Adolescent Patients?

Extremely Appropriate	Very Appropriate	Appropriate	Indifferent	Unappropriate	Very Unappropriate	Extremely Unappropriate

2 What are the most useful elements of the Patient Information Manual? Please give your reasons.

3 What suggestions for changes and additional features can you make to improve the Patient Information Manual?

4 Could you rate the Patient Information Manual overall, on a scale from extremely helpful to extremely unhelpful?

Extremely Helpful	Very Helpful	Helpful	Indifferent	Unhelpful	Very Unhelpful	Extremely Unhelpful

5 Have you any other comments that you would like to make on the Patient Information Manual?

fig 5.32 evaluation questions for the PIM

The evaluators included 4 Adolescent patients (Adol), an Adolescent Specialist (AdolSp), a Play and Recreational Specialist (PlySp), a Children's Teacher (ChTchr), a Paediatric Social Worker (Soc Wrk), a Nurse Educator (Nrs Ed), a Charge Nurse (ChNrs), three Nurses (Nrs) and a Doctor (Dr). The evaluators received an outline of the main pamphlet themes that they could refer to while the pamphlets and activities were presented to them in turn. Any comments they made during the presentations were noted. Any evaluative comments and suggestions that relate directly to specific pamphlets and activities are included alongside the description of these pamphlets and activites (pages 71-91). The comments from the evaluation of the overall design of the PIM, including the results of the attitude scales can be found on page 92.

5.2.4 rights/informed

The importance of keeping informed and of knowing your rights is the main message of this pamphlet (fig 5.3-4). The accompanying activity associated with the pamphlet is a passport/ journal. This offers patients a note book in the form of a passport in which they can record their hospital experiences (fig 5.35).

fig 5.33 inside of rights/informed pamphlet

The pamphlet demonstrates how official information is presented alongside quotes from staff and adolescent patients (fig .33). The printed quotes are selected from adolescent and staff comments made during the interviews and questionnaire survey, and are presented in circular texts to increase participant interest and involvement. Quotes include adolescents' opinions of their doctor's knowledge, and staff members' observations about patients understanding of their rights. Adolescent patients' rights were addressed by including information on the Privacy Act, patients rights, and informed consent along with patients responsibilities.

evaluation

Evaluative responses indicated that this pamphlet was one of the most useful ones (Nrs, ChTchr), Evaluators stressed the importance of adolescents knowing their rights (Adol) and how informed consent, confidentiality, rights, and responsibilities were all major issues for this age group (Adol Sp). Positive comments were made on the balance of rights alongside responsibilities (Nrs, PlySp and ChNrs).

Evaluative comments made about the passport/diary showed that this concept could have a diverse range of functions depending on its design and use. The passport was designed to give patients a sense of identity, offering them an opportunity to record their treatment, medications and feelings. While some evaluators felt that the information patients write in their notebook should be for their own private use, others suggested these books should be shared with patients or hospital staff. *'Perhaps it would be more valuable for teenagers to write their notebook privately so they can really express themselves and focus firstly on a notebook as a therapeutic tool'* (ChNrs).

Adolescents could be encouraged to talk about their feelings and this could be kept on ward and fed back to the staff to help them to understand what the patients feel. This would make adolescents feel like they were being heard' (Adol Sp).

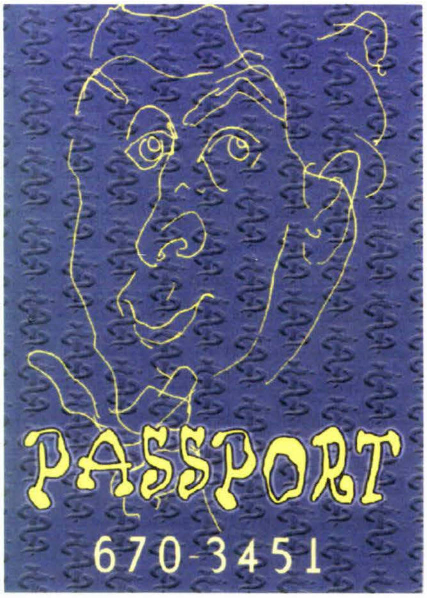


fig 5.35 passport/diary cover

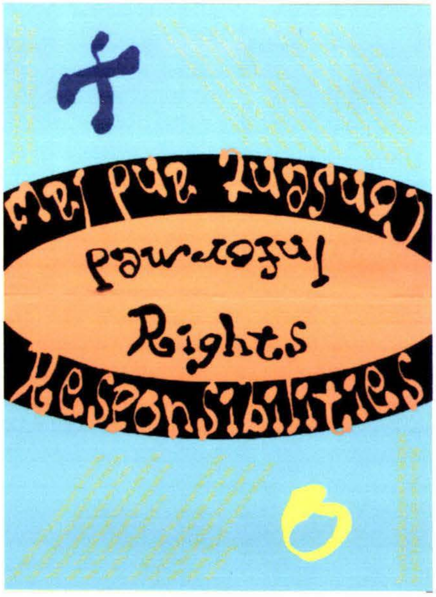


fig 5.34 outside of pamphlet

'Better if its more practical and not emotive or emotional. They could record official information: Questions to ask Doctors and leave some space for patient to write down the answers they are given. They could keep this or have it among their hospital notes' (AdolSp).

'It would be really useful for them to have a summary of their treatment and condition from the doctors. They are given information before they leave but quite often they don't seem to understand what's been said' It was also suggested that instead of autographs, having a space for *'Friends I met'* or *'Contacts I want to follow up'* would appeal more to adolescents (ChTchr).

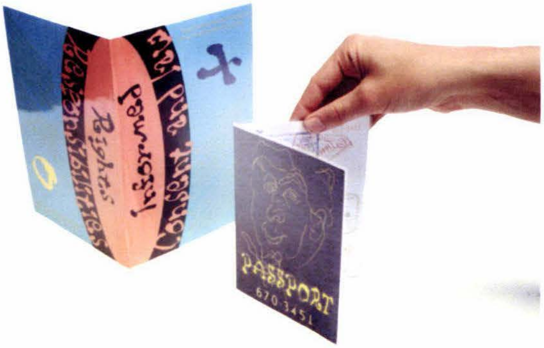


fig 5.36 pamphlet and passport

5.2.5 private/space

Privacy and personal space is addressed in this pamphlet (fig 5.37-8). The associated activity is a maze. The maze is created in the form of the wards, corridors, lifts and carpark of the hospital building within which the patient can orientate himself/herself. The doctors and visitors have to be located among all the other people typically found in hospital, and their path through the labyrinth of the hospital must be found. (fig 5.39 on the following page is a conceptual model).

The patients' quotes on the pamphlets express the importance of privacy, while the comments from staff suggest how patients can personalise their space without causing problems for other patients (e.g. wearing headphones and putting up their own pictures).

This pamphlet contains information about the services available for adolescents in hospital. This includes information on adolescent patients' access to spare rooms, coffee, videos, telephone, and the library along with who to contact if permission for use is required. It also includes an outline of the hospital timetable (meals, rounds, and shifts).

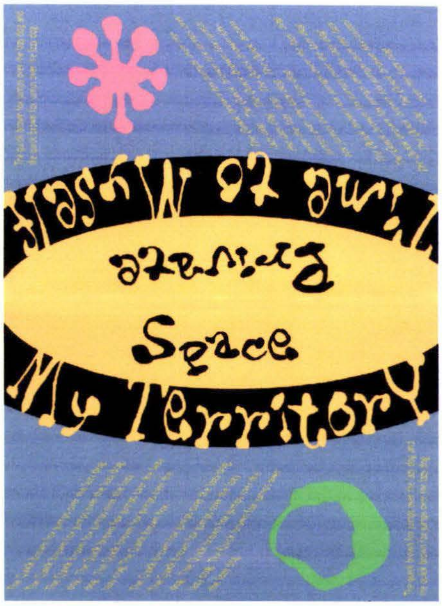


fig 5.37 outside of pamphlet

This information would need to be tailored to the specific regulations of individual wards and different hospitals.

evaluation

The concept of the Maze was particularly appreciated by the Nurses who were involved in the evaluation. *'It would be useful in helping adolescents 'understand some of the pressures that staff face'*, *'effectively illustrates the patient's place in the scheme of things'*, and is *'a humorous way of introducing patients to the wider picture of hospital life'* (Nrs, Nrs).

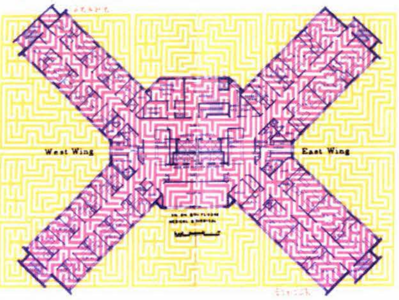


fig 5.39 hospital maze

fig 5.40 pamphlet and maze

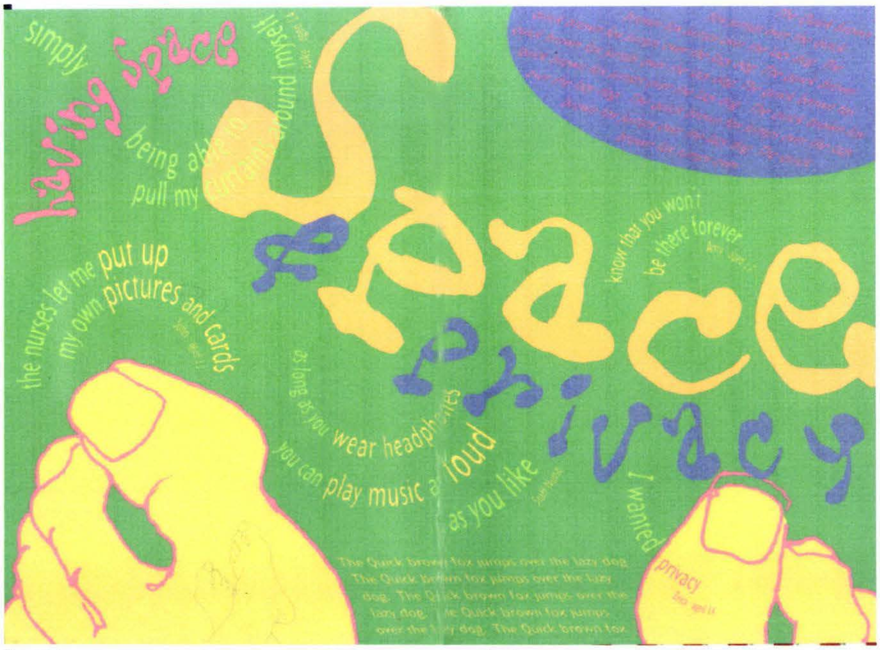


fig 5.38 space/private pamphlet inside

Suggestions included basing the maze on the actual hospital so that it could be used as an educational resource that could link with a weekly tour of the hospital for adolescents (Adol Sp). The size of the maze was seen to be important. It was noted that a firm card that was no larger than the hospital bedside table should be used. This would insure that those patients whose hands were restricted with IV lines could still readily use the maze (PlySp).

5.2.6 ask / staff

This pamphlet stresses the importance of communicating with hospital staff (fig 5.41-2). The associated activity consists of dress-up paper dolls (fig 5.43-4). The aim of this activity is to strip the staff of their authoritarian trappings (white coats, uniforms) and enable patient to engage in positive role play and visualisation. The pamphlet quotes suggest patients should 'Talk to staff, ask them questions, and ask for information and photographs.' The pamphlets also contain useful questions to ask doctors and nurses regarding treatment. They describe staff roles.

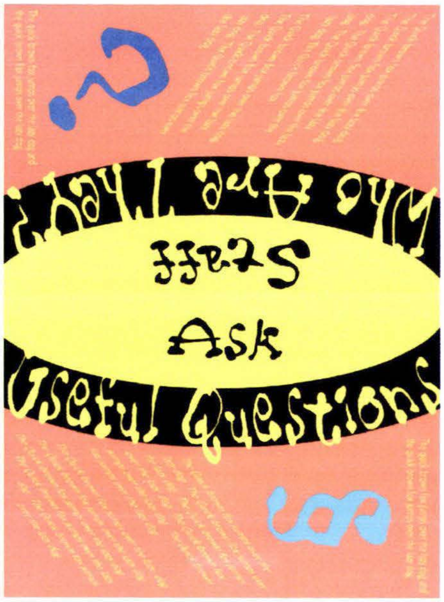
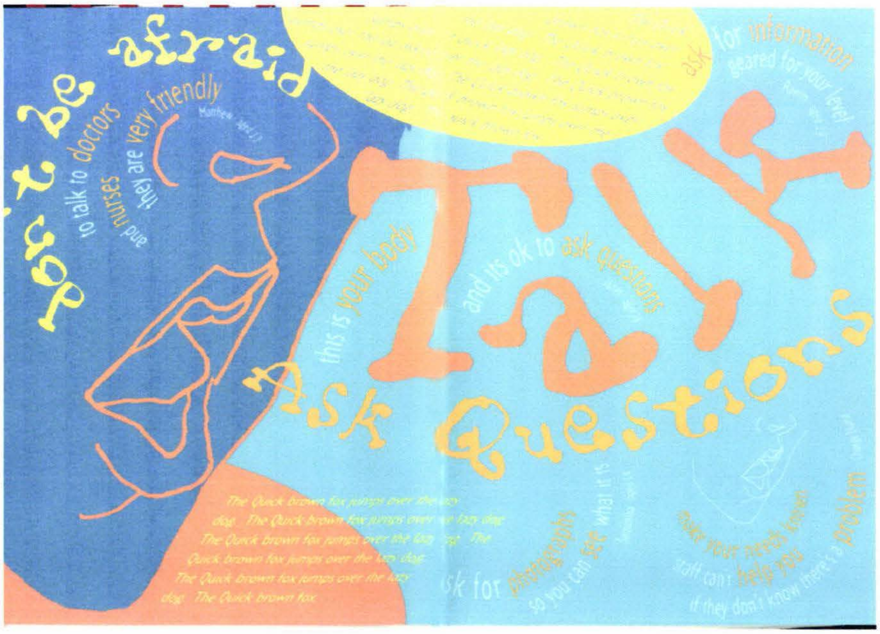


fig 5.41 pamphlet outside



fog 5.42 ask / staff pamphlet inside

evaluation

Having a section on asking questions was considered to be important by the evaluators (PlySp, ChTchr, AdolSp, Adol, Nrs) as one adolescent explains *'its great to be told that it's okay to ask questions'.* It was also considered helpful to give patients information about the hospital staff, what they do and how to recognise them (ChTchr, ChNrs). One evaluator suggested that perhaps they could be presented as a family tree (ChTchr).

It was also noted that it may be unproductive to give adolescents the message that staff are friendly. Staff must sometimes administer painful procedures and must take on a role of authority not one of friendship.

Out of all the activities included in the PIM, the paper dolls generated the most discussion, suggestions and laughter. One evaluator described it as an interesting concept, with a good premise that had the potential of helping patients express their relationship with the hospital staff, but warned that it would need to be evolved to ensure that it was palatable to staff members (PlySp).

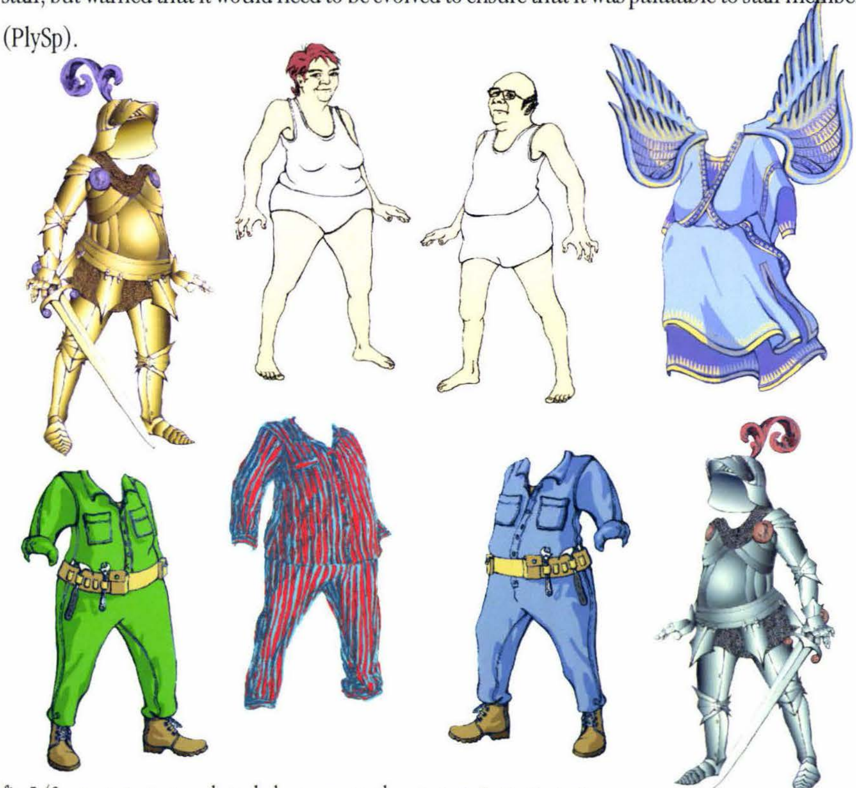


fig 5.43 paper dolls and costumes

One of the first observations made was that the male and female dolls were both conforming to older European stereotypes of doctors and nurses which did not fit with the current reality. Doctors and nurses now come from a greater diversity of ethic backgrounds and many of them are considerably younger (ChTchr, ChrNrs, Nrs and PlySp). It was noted that this activity could have the negative effect of stripping nurses and doctors of respect and could possibly be read by staff as a put down. It was suggested by one evaluator that such an eventuality could be avoided by changing the wording from 'dress a doctor' to 'what relationship would you like to have with your doctor?' and instead of having two staff members, to have an image of the patient with a staff member so that an adolescent can use this activity to define their own roles (PlySp). This was seen to be a natural extension to the role reversal that was implied by dressing the doctor or nurse in pyjamas *'it was an interesting idea to dress the staff as patients - they are just like us'* (Nrs).

A number of new costume ideas were also suggested by the evaluators including: Staff uniforms to give a sense of reality (PlySp), more science fiction, playstation, hi-tech costumes to appeal to boys, more negetive roles for example a witch (ChNrs), and more cultural and ethnic diversity in costumes (Adol Sp). It was suggested that including a T-shirt with Maori writing across it and a brightly coloured Pacific Island shirt would help Pacific Island and Maori patients feel included (Maori Research Unit). It was also noted that the tabs needed to be constructed in a less slippery material. The paper dolls were difficult to replace into the sleeves (Adol). A few of the evaluators described the illustrations as 'great' (PlySp, Nrs) and commented that the dolls would provide 'a great conversational opener' (Nrs).

fig 5.44 pamphlet and paper dolls

5.2.7 give/receive

This pamphlet is designed to encourage adolescent patients to seek support from others and give feedback to staff members (fig 5.45-6). Two certificates are included as an associated activity for patients to fill in and give to the staff members or their care givers. A 'thank you' certificate for positive feedback, and 'room for improvement' certificates for constructive feedback were part of the package (fig 5.48-9). The quotes from staff and patients in this pamphlet suggest that it could be helpful for patients to share their experiences by finding others who have been in the same situation. It is also suggested that patients should give feedback to hospital staff. While this pamphlet encourages patients to share their experiences to help others it also alerts patients to the support services available inside and outside the hospital including support groups, chaplains, and Youthline.

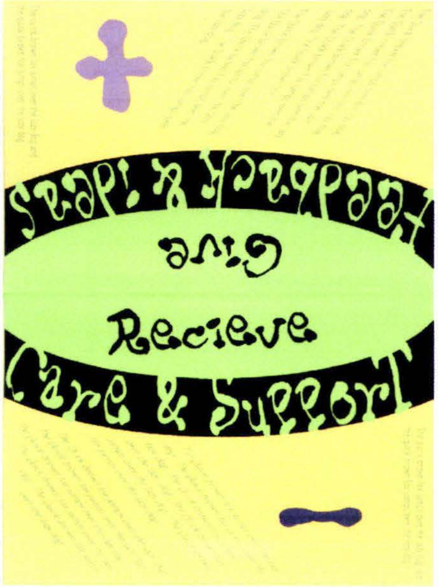


fig 5.45 pamphlet outside

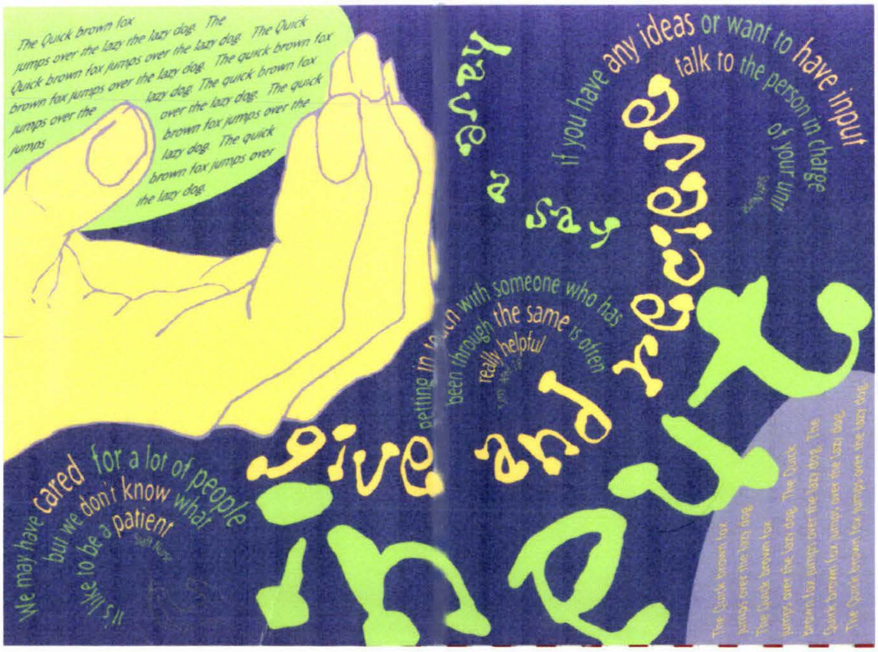


fig 5.46 give/recieve pamphlet inside

evaluation

Although there was support for including information on the existing support groups in the hospital and community it was noted that this information would have to be individualised for each hospital and region especially if it were to include phone numbers for local support groups (Soc Wkr, AdolSp).

An advantage of the PIM is that it's contents can be updated and replaced at any time and any number of pamphlets and booklets from national and regional organisations can be stored within it.

fig 5.47 pamphlets and certificates

The certificates were also considered to be a useful idea although some of the staff were apprehensive about the 'room for improvement' certificates. Some commented that: *'patients might leave and stash 50 'room for improvement' certificates in their beds, one for each staff member'* (NrsEd) and *'I would feel a bit dejected if I received any of those'*(Nrs). It was suggested that this pamphlet could be improved by being worded more positively like *'It would help me if...'*'(Ply Sp).

CERTIFICATE
of
Thanks for Your Help

o

really appreciated
our help and support

fig 5.48 certificate of thanks

CERTIFICATE
of
Room for Improvement

To:

In the future
it would be really helpful if...

fig 5.49 improvement certificate

5.2.8 ward/specific

This pamphlet contains information specific to the routines and practices of the ward in which they are used (e.g. visiting hours, needs of others) (fig 5.52). The associated activity is a 'feeling' clock (fig 5.51). This acts as a mood indicator and can be attached to the patient's cubicle or bed to give them a way of expressing their feelings to other patients and staff.

evaluation

Three of the evaluators spoke specifically about how they could see the 'feeling clock' being used in hospital: *'should be on the wall above your bed, or standing on your bedside table like an alarm clock'* (Adol), *'I would like one for my door!'* (ChrgNrs) and *'you could attach it anywhere'* (PlySp). One evaluator questioned the value of having a 'Going home today' option as she pointed out that *'when patients are going home, they're out of there.'* She also noted that it was important that the 'feeling clock' did not give options that patients didn't have like 'Private, keep out' and suggested that the pronouns we, they, us and our were not used as they were not inclusive (PlySp).

fig 5.50 pamphlet and clock

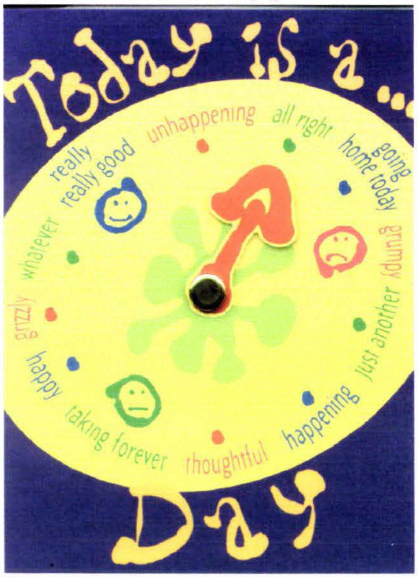


fig 5.51 feeling clock

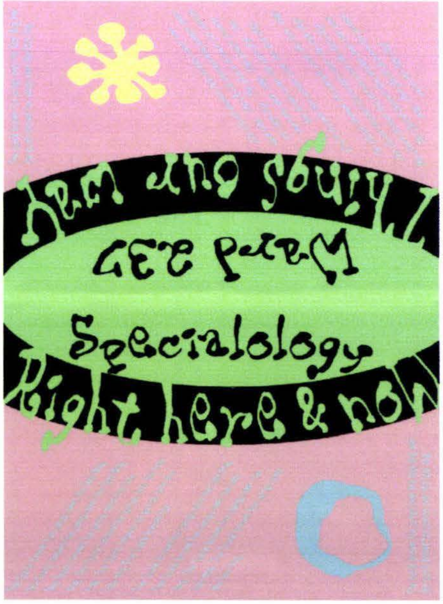


fig 5.52 ward/special outside

5.2.9 feel/laugh

This pamphlet carries messages from adolescent patients about feelings including 'be positive, don't bottle feelings up, its OK to be sad, and laugh'. It contains an outline of the grieving process and information about adolescent development (body image - sexuality) (fig 5.53).

The associated activity is a folding word puzzle (fig 5.55-7). This is a word association activity to help patients identify key emotional words and make them aware that other patients may also have had the same feelings and emotions.

evaluation

The feel/laugh pamphlet was considered to be especially helpful for adolescents as the following comments show: *'I think it is really good information because I think teenagers need to talk about their feelings so they know where to go for help and this gets them to express their feelings'.* (Adol) and *'Specific to adolescent feelings/fears/concerns etc. Encourages patients to talk about their feelings'* (Nrs).

The suggestions indicated that the wording of the adolescent patients' quotes may not be the most appropriate. Although the concept of using quotes was approved of, evaluators found that some of the advice that adolescents had for others in this section was too authoritarian. *'Its important to send the message that 'feelings are ok' rather than the more prescriptive 'be happy', especially when adolescents are upset and angry'* (PlySp). It would be better if adolescents were encouraged to talk to friends, and adults rather than just staff (Adol Sp).

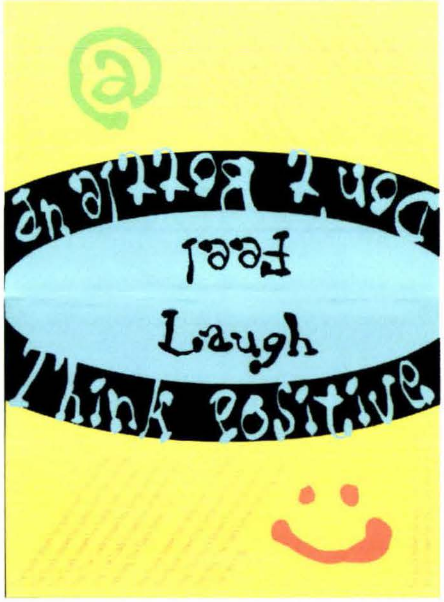


fig 5.53 feel/laugh outside

fig 5.54 pamphlet and game

The word game was described as useful because as people played with it they would subconsciously be taking in the information (SocWrk). It was also considered engaging. *'The word game is fabulous, I would play with it for hours. I didn't find it tricky, you just have to match the colours'* (Nrs). It was suggested however that the construction material needed to be much stronger than paper if it were to survive all the folding.

fig 5.55 word game folded to 'grumpy' and 'brave

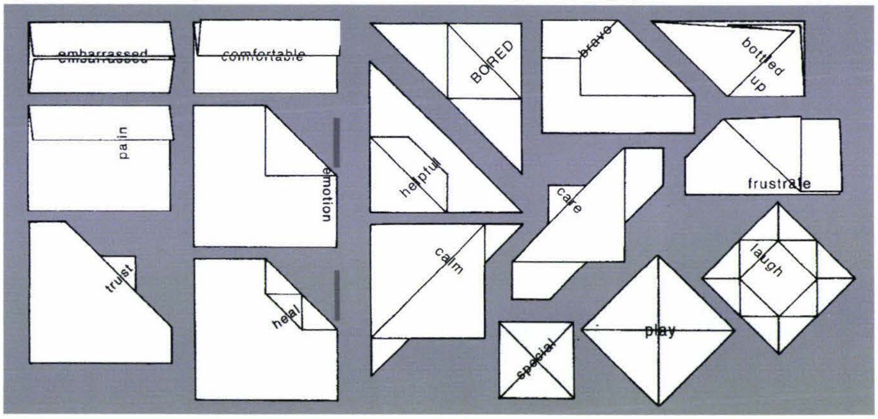


fig 5.56 some of the possible folding solutions

fig 5.57 front and back of the word game

5.2.10 odds/ends

This pamphlet is designed to contain the hospitals own pamphlets and any other concerns that do not fit into the other categories (fig 5.58).

evaluation

Staff suggested that this section could include: A hitch hikers guide to hospital including things like 'a thousand ways to enjoy your hospital stay' (PlySp) and information to help adolescents manage their sleep such as not playing high energy games before bed. (AdolSp). This pamphlet could also be used to contain comments and advice generated by adolescents themselves (Nrs).

5.2.11 pain/ouch

The pain/ouch pamphlet contains information on pain, pain relief and pain specialists alongside a range of alternative strategies for dealing with pain (fig 5.59). Patients are encouraged to make their needs, regarding pain, known early.

evaluation

Although one evaluator felt that pain was too individual for any resource to be of much help (Adol Sp), others suggested that the pamphlet should include letting adolescents know that they can ask for pain relief, especially before physiotherapy (ChTch), and could also contain information from the Pain Trust collaborative(PlySp).

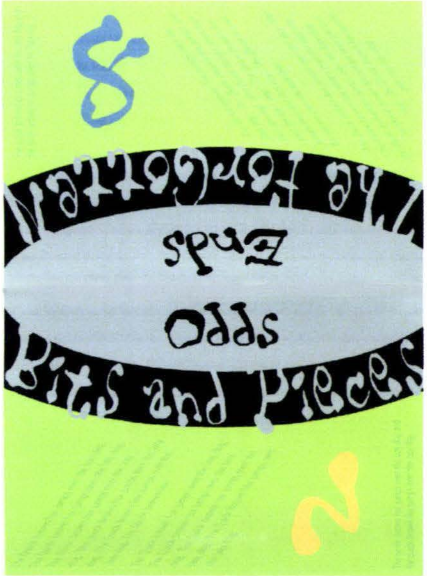


fig 5.58 odds/ends pamphlets

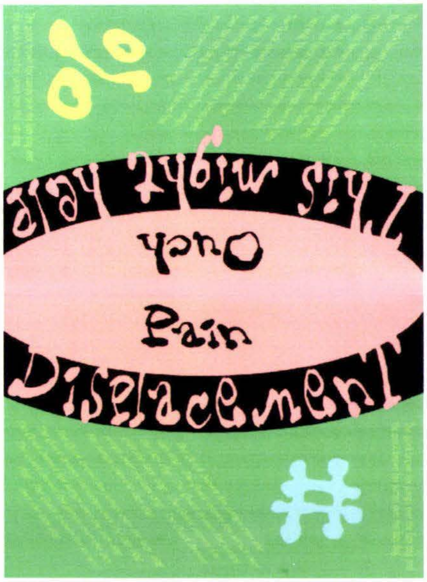


fig 5.59 pain/ouch pamphlet

5.3 evaluation of the PIM

As outlined on pages 78-79 the health professionals and adolescent patients who commented on the pamphlets and activities also commented on the PIM as a complete package and rated the PIM on two attitude scales (page 78). When participants were asked how appropriate the PIM was for adolescent patients two considered it to be 'very appropriate' (Adol, Nrs), while the remaining eight evaluators felt that it was 'extremely appropriate'. Although it was suggested that some of the contents may be better suited to the younger adolescent (AdolSp), some evaluators commented that, if the PIM was thoughtfully applied, it could benefit a wide age group (PlySp).

The evaluators were equally positive about how helpful the manual would be to them, with one evaluator considering it to be 'very helpful' (AdolSp) and nine indicated that it would be 'extremely helpful'.

5.3.1 suggestions

A range of suggestions for improving the PIM emerged from the evaluation. Most of the suggestions related to how the PIM could be made more inclusive of a wider audience. It was suggested that the inclusion of more illustrations would help those with literacy or ESL issues (SocWrk). An evaluator also drew the designer's attention to the need to use sufficient tonal range in the designs so that text and illustration could be readable for the colour blind (Nrs). It was also commented that the PIM did not yet address the needs of Maori and Pacific Island patients (AdolSp). The Maori Research Unit have offered to assist in finding Maori adolescent patients for subsequent evaluations. It was also pointed out that although this design would appeal to some/many of the adolescent patients, it would not satisfy them all (AdolSp, PlySp). However, the packaging system has been designed so that the existing design style and information can easily be modified and an unlimited number of pamphlets can be added to meet new demands as they arise.

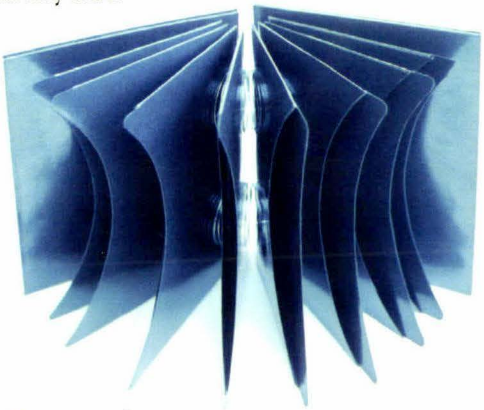


fig 5.60 the PIM ready to accept new pamphlets

conclusions

6

The aim of this research study was to determine how visual communications design could contribute to the health care and healing processes of adolescent patients through the design and evaluation of a Patients Information Manual (PIM).

This research was conducted using a holistic approach which took into account adolescent patients' perceptions of their hospital experience including their surroundings, feelings, and spare-time activities. The resources currently available to adolescent patients in hospital were reviewed along with existing forms of graphic design for an adolescent audience to establish the design criteria, typography, illustration and colour combinations which would be appropriate for the target audience.

The needs of adolescent patients were identified through a literature review and user-centred research involving 30 patients and 19 staff in three New Zealand hospitals.

The designer had to overcome major bureaucratic barriers during the research process before it was possible to obtain access to hospitalised patients and health professionals. Gaining ethical approval was challenging and time consuming, but necessary to inform this study.

The main research findings confirmed that there was a lack of information for adolescent patients and that existing hospital resources were not designed to communicate and appeal to this group of patients. There was also little recent research relating to adolescent patients' perceptions and needs.

It was found that adolescents were a population with diverse and changeable tastes and that in terms of design, no one graphic style would work for all adolescents. However, as a result of the research, it was possible to determine that harmonious combinations of bright primary and secondary colours would be most likely to have favourable appeal, as well as to have therapeutic effect for hospitalised adolescents. It was also found that adolescents would be more likely to appreciate information presented with a combination of image and text (for example comics and cartoons).

The criteria used to inform the final design of the PIM packaging system, pamphlets and activities were generated as a result of the research findings. The survey findings confirmed that most adolescent patients would access the PIM while in their beds, and that many of these patients did not have the full use of both of their hands because of I.V. needles. Hospital staff suggested that the PIM needed to be able to contain both new and existing information in a form that could easily be stored, retrieved, reorganised and distributed. With these criteria in mind five appealing, fun, and user-friendly packaging systems were developed. These packaging systems were then evaluated by hospital staff and a designer for their ease of use and appeal.

The findings also suggested that adolescent patients' would benefit if they were better informed about the following: patients rights and responsibilities; the hospital routines and services; staff/patient communications; support services; and how to understand their feelings. A series of colourful pamphlets, activities and games were designed to communicate this information alongside relevant comments and advice from staff and patients. During the final evaluation, of the form and content of the PIM, comments and suggestions were recorded about the relevance and useability of these pamphlets, activities and games.

The prototype PIM received high acclaim from hospital professionals and patients. The evaluators contributed a variety of suggestions to improve the PIM while also commenting that the PIM fulfilled a real need that was not currently being met in hospitals. The PIM has been recognised by both health professionals and users to be appropriate and extremely helpful in addressing adolescent patients' needs.

This research study has also indicated that the scope and dimension of Visual Communications Design is much broader than is currently practiced by most designers. To be able to integrate the complexity of social and personal needs into a design solution involved a more empirical and holistic approach than is normally associated with a communications design process. This research study points to the significant benefits to adolescent patients that is made possible by using a more interdisciplinary, empirical and user-centred design approach as demonstrated by this thesis and by the positive feedback from hospital staff and adolescent patients:

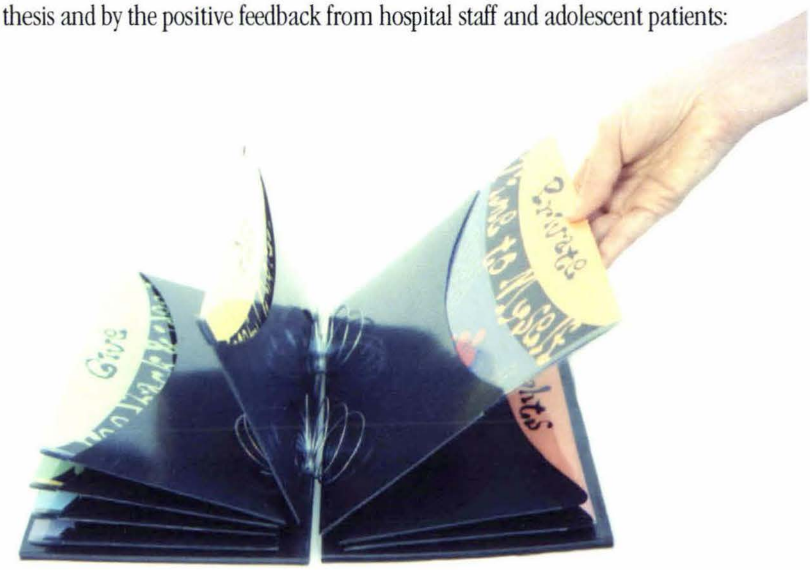


fig6.1 replacing the pamphlets into the PIM

'Its important that teenagers are informed - so I think it's a great idea' (Adol).
'This is a brilliant idea and I would love to see it up and running in hospital' (NrsEd)
This is an excellent tool and will be extremely useful to any group working within the health system for teenagers' (ChNrs).
'Great to see something designed in such a well researched way for the public sector. Excellent!' (SocWrkr).

A number of the comments also pointed out that the PIM met real needs:

'It contains a range of relevant and important issues not addressed by other parts of the health system and it helps to bridge the gap' (AdolSp).
'About time! Adolescents have been overlooked for too long. They are a group that need to be considered independently' (Nrs).
'Fulfils a need not being met elsewhere. It will be invaluable for small hospitals, there is nothing out there! And it will be useful in big hospitals where there are the people resources to apply it' (PlySp).

Other comments noted the PIM's value as a communications tool:

'It is an excellent discussion tool. You could fire it at a patient if you were really busy without any preparation and then come back and talk about the issues it raises' (Nrs).
'This would be a great way to open up a conversation, this would really help people to discuss things, all of the PIM is like that, it would be a good catalyst' (Nrs).

There was also positive comments about the amount of text and use of quotes:
'Information reflects the views of teenagers. Provides 'cues' and hints rather than screeds of info. Beautifully presented' (ChNrs).
'The pamphlets make you want to read the message, there isn't too much text on the page' (Nrs).
'The quotes are great' (PlySp).

fig6.2 PIM containing activities & pamphlets

There was a keen interest to supply the designer with the necessary official information to engage adolescent patients in an ongoing trialing and refining process. All participant staff were keen to use the PIM in hospital.

Many positive comments were made about the design of the PIM especially for its use of colour they included:

'The bright colours make it easy for teenagers to relate to - they make people want to read them' (Adol).
'Colour, design and format are very appealing. Innovative!! I think it is superb' (ChNrs).
'Appealing presentations, - easy to access, colourful, useful, easy to read information' (Nrs).
'Very user-friendly. Great design' (NrsEd).

One of the few problems evaluators identified was that the PIM would be easy to steal:

'Really like the spring book, it makes it easy to access the information, the only down side is that people would steal it' (ChNrs).
'It couldn't be left on a table incase it was stolen' (PlySp).
'The spring is really nice and its handy to open. It's cool, I could play with it for ages' (Adol).

Since completion, this research project has also been presented as a paper in the 3rd Pacific Rim Conference of the International Association of Adolescent Health, Lincoln University, 25-28 June 2000.

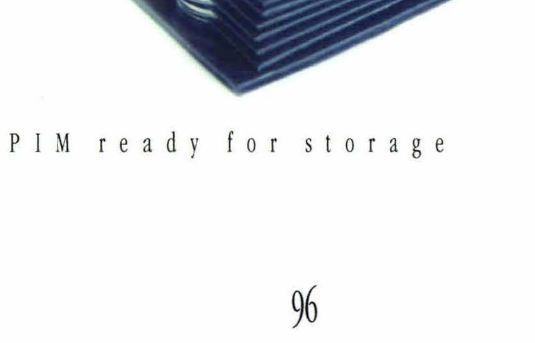


fig 6.3 the PIM ready for storage

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appendix

The information gathered from the patients questionnaire and staff interviews provided the basis for the development of the PIM. This appendix contains extracts from the staff interviews (pages 102-112) and comments from the patients survey (page 113-119). The complete interview transcripts are available through the author.

staff interviews

existing resources

there is a lack of resources

D: ***"What about any other resources or activities that you may have seen or resources that people use on the ward, books or activities or ?"***

C123: ***"Not really, No there seems to be a terrible lack. No an absolute lack. A terrible lack of things, I haven't seen anything."***

C2: "I mean, basically we have jigsaws or we suggest that they bring in things themselves from home."

they're unbelievably bored

N: "Can you describe any problems or challenges that you have encountered in dealing with adolescent patients. ***Boredom. Complete and utter boredom. That's the major problem. Mainly that's with the 13-16 year olds and they're just unbelievably bored."***

D: "Do they do anything? do they just look bored or do they actively do things?"

N: "They don't actively do anything. You've actually got to go and find something for them to do because, on this ward, we don't have anything of that sort for adolescent people. ***We say, "here, have a magazine". But that doesn't keep boys occupied. It would maybe keep a female occupied, and it's mainly males that are so bored. And they want to get up and walk around. And trying to find something for them to do*** *. There's the kid's ward, and we often ring them with the 13-15 year olds and say "please come up and have a look at them and get them to do something".*

D: "and does that work quite well?"

N: "It does, it does. ***Some of them, the things they get them to do are just a little too young for them. Cause they bring in all sorts of things like colouring books. But that's just a little bit too young for a thirteen-year-old."***

D: "If you could imagine something that could be given to adolescent patients to help them through being in hospital, does anything come to mind, would it be games based, or activities based or information?"

*N: "****Not information, I think they'd die of boredom. Activities and games I think.*** *Even one of those little game master things, they could occupy a teenager for hours and hours, but they often don't have them. Parents don't have them. TV's, but that's the same, it costs heaps of money."*

existing resources are inappropriate

D: "Can you describe any problems or challenges that you have encountered in dealing with adolescent patients?"

N: "Um, Communications is a big one. But I'm also a teacher in NLP neuro-linguistic programming, so I have no problem communicating. The biggest problem/challenge we do have is finding appropriate work for rheumatic adolescent children, and appropriate work and diagrams to illustrate their infections and their problems."

D: "Is this because there is none available?"

*N: "**Because the ones that are available are inappropriate, they were written a long time ago and they don't meet clinical standards.** So at the moment we are trying to design a new chart for the rheumatic fever children, which we've no idea how to do."*

D: "Is it because the illustrations are outdated or because they are inaccurate?"

*N: "Because **the illustrations are quite horrendous.** One is a bug - a streptococcal bug - with its finger in one ear and coming right out the other ear. It has big feet that look like something out of a horror movie, actually quite off-putting and frightening for children to think that they have this thing inside them that is alien. What we're trying to do is make it more correct in terms of more culturally appropriate, more aesthetic, and less frightening especially for adolescence who interpret things so vividly. So we're trying to make it much softer and a lot more fun."*

we have resources for children

*S: "Yeah, but you know, that we're starting to build up resources like book resources, creative resources, video resources, pool table. **So we've got the resources. But once again, they're all targeted in with younger school age children and babies so they're all mixed in together. Whereas if we take these and put them in an area specifically for adolescents or young people (whatever your terminology is), it would make life much more comfortable for them and easier. Um if your looking back, its like you put a whole lot of young people together in a room you're asking for mischief and you're going to get it. They're a difficult patient loading because, um, when they get bored and they're uncomfortable they will act out and they build off of each other. So they are challenging, particularly...** "*

*S: "Yeah. Am I aware of 'any publications, resources or activities that have been designed to help patients?', um, I think there is very little written in terms of the whole, for children and young people in hospital. The only brochure about going into hospital is done by children's health liaison group, for your child going into hospital. **So I know of no publications that are available, and yes there is a need of one, a major project.** I think that within hospitals individual activities have been designed"*

adolescent needs

adolescents have big needs

S: "I guess, if we look at medical staff, which is the one I know most about, the difficulties we have with medical staff in dealing with adolescents is we're very organ based or disease based in our approach. And that's often how we're funded. And that's the way we're trained. And I think *adolescent issues don't often fit comfortably into that. So you get plastic surgeons who are very comfortable in dealing with their operations and their burns, and, but, if they have to deal with other things like a young person who may have a substance abuse problem, or hasn't been in school for two years, then their not interested in that because it takes up time, and it takes up money, and they don't want to deal with that anyway.* ***So you get a lot of doctors in the hospital setting who don't want to deal with adolescent stuff. They just want to do their bits. And so there's a bit of unwillingness, I guess, in to recognise adolescents as being a special group that have got big needs.*** *And we have more than 4000 patients a year in the adolescent age group. A big, big, group. A lot of them are obstetric, gynaecology, trauma patients- which are the biggees in adolescent health.* ***They're a group that, if we could have some input while their here, we could have a huge health gain in our community.*** *If you could pick up a teenage mother, here and spend time with her about child health, community support, so if you could do that here before they get chucked out, it would have a huge impact. A positive impact for the mother and the child "*

social and financial needs

N: " I think that that's the biggest problem or challenge. I think that particularly adolescents don't have, don't bring with them, any resources into this. So sometimes it would be easier if they did identify as a child I think, um. In particular things, I looked after someone not very long ago, who, um, was diagnosed with a severe haematology condition, and actually married very young. And his support person, who was his girlfriend, major support person, they actually married very young, and so in terms of resources you had someone who was strongly committed to him and working on his side, fighting on his side for everything. He was ah, um, he was ah, um, that was his strength and a big resource that he brought in. But, on the other side, every time they had the possibility of time out from treatment, time out from hospitals, you know, you'd often say to him, well why don't you and your wife just get away and go somewhere? And they're sort of like, well, how are we supposed to do that? We don't have any money, um. They don't have friends who have houses, you know. ***Where as when your dealing with adult, perhaps, who are in their forties, they have their incomes, they have their houses, and they've set aside a little bit of money in case something happens. And so they have possibilities because they have resources. Whether they are financial resources, whether they're sort of social resources, like groups of friends who say, 'look don't worry, we'll take the kids" ,um "no problems at all you guys, get off" or "why don't you go up and stay with someone".*** *Teenagers don't have, ah, that kind of organised life. They haven't sort of thought, well something might go wrong, lets sort-of-put a little money set aside, lets make sure we have these things. So even for me as an adult its really hard sometimes suggesting something that is useful um, in terms of actually taking time out, ah, looking after other aspects of their life, because they have very little resource.* ***And so we do sometimes have to be quite creative in terms of making sure that they're booked in with the social work department. That they are aware that the cancer society has things like, um, ah, some benevolent grants. Some special grants put aside, um, that you could develop a case for to say "well we need money for this", um, yeah so, those sorts of things, I guess that I find the hardest "***

need peer support

D: "so can you describe any problems or challenges that you have encountered in dealing with adolescent patients?"

C1: "they get bored."

C2: "and isolation it's probably from their peers"

D: "is their behaviour any different from adult patients or more difficult to deal with?"

C1: "they can tend to act up at times and be rather childish."

C3: "and they're worse when their friends are around. It's just adolescents really [laughter] acting up at times."

C2: "I think probably the main thing is the isolation, in that for them to actually be in hospital is removing them from their peers and from what is normal and so therefore that, in itself, is the big issue because ***they don't want to loose face in their peer group.*** *So if you're not there you loose, um, a spot in that group and that's their fear. Is that even though its often ungrounded - like th their obligations, and how they can, you know, get a fair treatment while they're in hospital. eir friends are often the opposite and actually fuss around them, they think they're going to lose their place and so they are very scared of being removed."*

C1: "and ***they work hard on maintaining their identity.*** *Dressing in their own clothes and lots of stuff they bring in from home"*

difficult behaviour

N: "You don't have problems with the short termers cause they're generally sick. They spend a day in recovery and they're out. Um, its your long termers that are often sick for a couple of days- three or four days. They come well quickly, but they need to stay in hospital for a longer treatment. ***And its when they're well that the hospital system starts wearing a bit thin with them. And that's when they start exhibiting deviant behaviour. Yeah, and its to be expected. Like we do expect it. Adolescents being adolescents, they get bored. They get cheeky.*** *You know, they tend to come from a wide variety of backgrounds. You know, a lot of our adolescents are street kids. You know, that's the smoking and playing with meths and that, and like cigarettes and petrol, and that tends to burn them. So its very difficult to provide any entertainment or any sort of discipline or anything like that, that a street kid hasn't heard or seen before and knows exactly how to sort of manipulate, and ignore and basically go ahead and do their own sort of behaviour anyway."*

parental involvement

C: "problems or challenges? I guess its, from our point of view, m because were not geared. I'm thinking of the younger adolescent group. ***We're not geared to looking after that group of patients. So the challenges are remembering to get that involvement with the parents and stuff like that.*** *Knowing when to get parent's consent and when not to. This whole thing of privacy. You know, trying to negotiate what you tell the parents and what you don't. Trying to decide whether that kid is actually capable of making adult choices. And sometimes they are and sometimes they aren't. And it depends on the extent of it. We've also had kids that maybe their parents haven't been able to be there with them - from out of town. Maybe 14 year olds or something like that who..."*

C: ***"The other challenges are to do with the whole control thing and the sort of acting out that you get.*** *And that's something too that some of us are more experienced at than others not. That there are some that are very good at dealing with adolescents and some that would [hiss, sign of the cross] back away from them and don't want anything to do with them, which is quite* *understandable."*

D: "Acting out in what way?"

C: [sigh] " ***Ah just either threatening type behaviour like 'well I just won't do it, I'm not going to do it and I don't care what happens, I don't care if I die, I don't care!' You know that sort of stuff, like either not taking pills or not doing something. Sometimes being a wee bit woozy, maybe. like um.."***

C: "and its not like a kids thing where you can bung a whole pile of kids in together and do an activity together. Adolescents are like, well I don't want to be doing things with that dork, or that other, and they don't want to be labelled even as sick or even as an adolescent. You know its like I am my own person and I don't want to be dumped in with, and have activities with, a whole lot of other people. "

suggested solutions

levels of understanding

N: ' ***But there are some things that I need to get them to do, like have treatments, or take medication and stuff. And its up to me to negotiate as much as I can, because ultimately they'll still go ahead and do, you know, they'll do what they want to do, and, you know, if they think they're losing face, they will actually choose not to have a treatment just to make you pay as an adult. That's just their mind. So you do need to negotiate.*** *What else? That, um, I think its really important for adolescents that they don't look at the same four walls all day, I'm really keen that they don't have free access to just what they want 24 hours a day because they become bored. It just becomes their routine and therefore they get bored with that. Therefore, even that doesn't work any more. So its important that either they stay in their rooms, on their beds, doing a bit of school work or whatever, and then you actually move them into a different room, like the playroom (what ever you want to call it) and that gives them a variety of rooms to look at. And that keeps them in a routine. And also it means that they don't get bored with the one environment.' I mean, sometimes, sometimes your on the border-line.* ***I mean you educate them like an adult but they still have quite a childlike impression of what you're trying to tell them, which can be quite detrimental. Um, so its quite important to gauge what sort of level they're working at before you start.***

it's about communication

D: Can you describe any information concepts or ideas that you have found useful in helping patients?

C: ***Probably getting someone in of their own age and getting them to talk about their experience is the most, is one of the best ways of doing it.*** *We, um, in the study I did, was about information and how it moved,and the amazing things that goes on in the ward amongst patients,um, and how you know. They compare how they're doing with each other and they talk to each other about this and they you know. I had that the other day and this is what happened so we actually "*

C: "Yeah. Yep, ***and often they don't know who's important when they come onto a ward. And learning to know who to seek assistance from is really important. I would say that communication would be 80% of our job.*** *Getting it right most of the time. There is a lot of other tasks that we do. But if you can actually communicate well with your patient, I mean your battles are nearly over.*

You know, I mean, with your patient and their family, you can't separate either, but you then have to be aware. Like I mentioned before, what information do you give? Do you share it and ,um, that all has issues around privacy act and, um, in a sense, if a patients relative rings us or you know a mum rings us and asks about her Joey, um, you really need to give the phone to Joey to tell her. I mean we can't - the privacy act has, I think, stifled the amount of information that can be shared."

they like to have input

N: "Um, and there are a few publications around but they don't come to mind at the moment. There's something called, oh I cant remember what its called, there are a few sort of handouts that we give out."

D: "is it something like this sort of thing? [teenage hospital guide]"

N: "I've seen something similar to this. And the youth service have some things. Sometimes they're related to sexual health or those sorts of things that are around the place. And also giving, letting adolescence know what their rights are, and their obligations, and how they can, you know, get a fair treatment while they're in hospital. So we have lots of publications"

D: "like the health and disability services booklet?"

N: "Yeah, and those sorts of things. ***And just knowing that there is legislation around. Getting fair treatment and access to information. Privacy, confidentiality and those sorts of issues.*** *Because they are really quite important one for adolescence. 'Have you any suggestions on what to put in a resource for adolescents.' Well, you know, that little book that you just showed me there. Something like that would be really useful"*

*N: "But, um, certainly t****hey, um, like to have input too. That's something else we do, we encourage them to write letters if they don't like something."***

D: "Oh OK"

N: "or if they have ideas "

D: "Who do you encourage them to write to?"

N: "I encourage them to write to the General Manager or to the Business Manager to express their ideas so they actually have a "

D: "so maybe a little note to say, if you think of anything ask who to "

N: "yeah, I think that it's really important for adolescents to"

D: "have a say."

N: "have a say, yeah, and make upper management aware that "

D: "they exist.

N: "yeah, and that they have got ideas. And that they want to have an input and a say in how decisions are made."

need to use their own voice

T1: "They tend to use a more medical model and what we're trained to do is give the children back as much control"

D: "autonomy"

T1: "Yeah, and how much can you regulate yourself. Not regulate yourself, but what can you do to help your state, yeah and that's it. And like recognising where you're at. How much you can manage, and how much somebody else needs to manage for you. Knowing the difference. ***In fact giving back the kids their autonomy, then they can do an awful lot for themselves. And we're quite often just walk strait over the top of that as well. So not only do we have, are we looking at, the model of adolescence, its like, how do you get that out to other professionals who don't recognise adolescence as being something else apart from children who make a lot of noise. What do you do?"***

D: "Is that one of the biggest things that single out adolescents from other groups?"

T1: "I think its their stage of development that makes them different. You know, they're risk takers at that age. They're experimental, they're trying to find themselves, they're using other peoples identity to work off. Like if you say to a young child 'your doing a really good job there', they'll just accept that as a fait a complis. Where as adolescents want to question more than that, 'why did I do a good job?"

D: "why are you saying that "

T1: "Yeah, are you being condescending? What is it about me that elicits that sort of conversation? So I think they need their own space."

*T2: "**And using their own voice as well, is another thing, is encouraging them not to be positive, oh still to be positive about themselves but also to like be able to question doctors medical about what is happening with their own body"***

*T1: "**It takes a fair bit of courage to stand up to a doctor and ask good questions"***

T2: "Just learning that its O.K. Hey its O.K. to ask some of those questions"

it's easy to gatekeep

T1: "Mmm, quite often were just physically feeding that into them, what I see in the things for adolescence, not only is there a play specialist or an adolescent specialist working alongside them, there is an information bank over there that they can go and do themselves, so they're not always relying on us to feed them what we think is appropriate, ***you know its very easy for you to gate keep and to make an unconscious decision about what's accessible for this child, what you think they need to know,*** *whereas children might start of on one tangent and then get hooked into something else and not realise that they were interested in that, you know that particular thing about it, we all do it when we go to the library, start of with one thing in mind and then learn a whole lot of other stuff that works along side that particular one thing and if its always an adult feeding in information then you stop that wider knowledge base happening"*

T1: "and that's giving them back those ideas, not putting words in their mouths its giving them the concepts to get out there and do it so they're proactive for themselves, those kids are smart enough, and I guess that's what I want to see, its those concepts and those ideas that I can pick up and use, to say have you thought about this?"

information to include

contact information

D: "I guess from my point of view I'm putting together a resource for adolescent patients which will just be a general one. ***Is there anything that you could think of that would be useful to include?****"*

SW: ***"I think just having a list of agencies, of community based agencies - that may be helpful for them. I think that having a list of contact names of organisations (and even having a contact person for each organisation with contact numbers and addresses) would be good. So, if the patient did choose to access something in the future they could. Um yeah!"***

how to ask questions

D: "And do you have any ideas as to what that resource could be or what you might find useful or want to include?"

C2: ***"I think the idea of something that has games in it is a good idea, but I think also something that gives them the confidence to actually ask questions or explain to everyone else in the ward how the system works would be quite good so they understand, cause they often like make friends with the younger doctors or nurses and then when*** *the more senior doctors who are the bosses come along "*

C3: "the consultants"

C2: "the consultants and makes a decision they don't understand who he is or why because they've become friendly with the people that they see everyday. And so maybe how the system works."

C3: ***"the different levels of doctors or something."***

C2: ***"and how to question, how to actually question those people."***

D: "OK. Would it be possible to make a resource that would work across the wards that did that? I mean the levels of doctors and nurses are fairly consistent across all the wards."

C123: "Yep they are"

C3: "OK. That would be good."

rights, privacy, and consent

S: "I guess the main thing is . It's difficult because, at the moment, we haven't got enough. We haven't got much to offer them. But, I guess, ***if you can at least let them know what is available, that's a start. I think it would be also nice for young people to have some information on their rights and issues of consent, privacy and that sort of stuff. I would think mostly people aren't that well informed about their privacy and their rights to health,*** *and the health information that they have their parents something along those lines would be useful."*

*S: "****Yep, that's really useful too. When you talk to young people, when they're frightened about the whole experience, its very disempowering who the people are. Having a sense of what's going on and who everyone is, and where they fit in the hospital is, would be, very useful. Certainly the young people that I talk to with chronic or life threatening illnesses, the kinds of issues around fear and loss that's probably a whole other book. You need to write [laughter], you know loss of body image and previous things they could do and fears for the future."***

*S: "****Information, concepts or ideas....*** *I guess from my point of view when I see young patients that* *present with whether its a medical condition or an injury or if its an assault or whatever,* ***I think a couple of the pivotal things that I say to young people are one is getting the information to them and the other is treating them with a bit of respect*** *which is often something which they haven't often experienced certainly there is a huge difference in the way that we treat adolescent patients in our adolescent clinic that there is in you know a paediatric ward, we have an um.."*

design criteria

individualised packages

N: "yeah, we don't have a specific thing like that. Its usually more if people are having chemotherapy. You give them handouts about that sort of thing, there's nothing specifically targeted to adolescents. A lot of the information we give is verbal. But we've got specific handouts for people who've got, you know, chemotherapy, things and mouthwash. Whereas others, you know, sort of, they are all separate. ***The ideal is that eveyone has their own little package things. Something, but that's a long way off.****"*

practical for use in hospitals

S: "Yeah. You know, I have a booklet about teens in hospital if I can find that for you. And it just talks about the issues for young people in hospital, you know, privacy and that. And how to achieve some of those and that would be good information to adapt and put into it. And the other would be, you know, ***if you did that as a format that other hospitals could take and add into it. I could see some practical applications*** *whereas, you know, 'A Kids Guide to a Strange Place' was an overseas book. And the Americans tend to buy that and do that with their children. I mean there's been several attempts to do it in New Zealand"*

D: "For children?"

S: "For children. ***But they all go cartoony or use animal themes and they just don't work with children of this day and age. will I believe. And the other thing is that people want to do it as a colouring in and kids don't want to colour in like that when they're in times of stress they draw their own pictures and things like that. So, I would see a practical application more than the format of 'A Kids Guide to a Strange Place' (which has got huge amounts of work into it) but to put together, you know, an information pack. You know, of self esteem exercises and body imagery and understanding the body inside, you know, like a template of the body because many young people don't have"*** *...*

D: "I thought, like you said, if I create something which has a format and has a whole lot of different options..."

S: "Yep, yeah"

D: "Which means you can actually pull some out and put some in.."

D: "Or you know ,this is an inappropriate question to ask and this is, you know....."

D: "Your rights and your responsibilities."

S: "Yeah, it is you know. But in a way that's not confrontational. That helps them facilitate it, like you know, the reality is that you have a teenager sitting up on the bed here in an adult ward and saying ***'I'm an adolescent, you know, and therefore, you know, my right is to have this and this and this and its like yeah, and you know what's going to happen. (That) is, no one's going to***

answer his bell and all the rest of it. So it actually has to be practical as well as   and it shouldn't have to be like that.... But that's the reality. So, it is about practical things that works from both sides of the fence. *And, I think, that's where, if you interface with people in doing those sorts of things, (I wish I could find), the other one is about knowing your feelings inside you know, about the ups and the downs and the bumps and the rolls are normal pieces and who are the people that can help you if you have got questions to ask."*

D: "anger, and fear and sadness"

S: "all of those things. The impact of hospitalisation on you, on your peers. I think one of the other ones, is how to stay in touch with your community so they don't get lost. How their community and some tips on how does this community stay in touch with these young people. I'm telling you, the number of schools that stay in touch with young people are very very small after the first two or three days."

D: "really?"

S: "Yep. That's what people have to be able to do. But in terms of adolescents going into hospital that is what we need to do here. You know, you could do some of those things. Things that are easy to do, things that are hard to do but that you managed. Self esteem, so that people working in other centres may have some ideas. But you could do things like what's going on inside X-rays, How do X-rays work, how do blood tests work, that sort of thing. You might like to do . Yeah, so I think that that's what people need to do in hospitals ***is develop resources that people can actually use for complex type things. So that's what you should be gearing your information for, you know ask for information about, that's geared at your level,*** *ask for maybe photographs so you can see in advance what it is."*

D: "You mean create a demand"

S: "Yeah, I mean, you know, to say to young people understand what's happening to your body, you have to manage, um, and ask them. You can use examples of what you've seen here. People should be doing that around, whether they have a photographic, like this is a photographic book this is generic, but photographs that will help."

ideas to pick and choose

T2: "everybody's individual"

T1: ***"yeah everybody's different but what I'd love to see is an information pack that says have you thought about these ideas to use in like so you could pick and choose and match those ideas with that particular child or that particular circumstance or that particular feeling and then so that you put it together in a book for that child so that its a very individual book"***

D: "I mean something like a loose leaf folder only a bit more cunning where you could take and take away bits and pieces?"

T1: "It doesn't even have to [end tape] and if your working it through in a progression and you have to follow the book, blood tests you might pick out an art activity you have seen about blood tests, you might pick out another activity that you've seen in that book that deals with pain levels and how you can manage that and then put that into that child's book, so you have a concept book that, like dealing with feelings you know um..."

D: "Could you equate it to what you've seen in other age groups in terms of what you imagine it could be? or ***could you imagine what it might be?****"*

T1: "Oh like I think, I think there's times there that when you've got the kids together ***its having the skills to facilitate the talking between the peer groups, there's that side to it, there's having the written information for the children to access when and where they need it*** *overseas there are some amazing computer programmes floating around that children can access on their own diseases or diagnosis, and things like that, now we don't actually have access to those, so were starting right at the basic book technique and creating it through when we know that we don't have the modern technology that we know is available for kids to punch into like I've just seen in the states. I mean some of that needs to be vetted, I'd agree because we don't know what's appropriate and what's not, but through the internet over there I know there are chat clubs for teenagers as support groups if they're in isolation or if they have those one off diagnosis where you might have say 10 in a hundred thousand where no one else in your town has that sort of stuff, I mean yeah, those sorts of things,* ***how do you get contacts, how do you talk to people like that? um what support groups are out there, not at a disease or a diagnosis but at adolescence to get together and talk about what it's like to have a chronic illness."***

folder of brochures

D: "What did you imagine I was going to be doing when you first heard about my project?"

*N: "****When I first heard about your project I thought that may be you, when you were talking about the resource, that you were going to develop . I thought that my perception was that, maybe you were going to have some sort of manila folder with a turned up edge, and that you would have some stuff that sort of explained what the hospital services were, and what was specifically there for adolescents. And then, maybe, some other little pamphlets, like looking after yourself or keeping yourself safe. And, um, what your obligations and rights are. And things might be and you know just some brochures that you could whip out to look at and um. And also a feedback sheet to say how they'd found it and what sort of things, ideas, that they'd have for "***

D: "feedback sheet to whom?"

*N: "****to um, that could go to whoever was coordinating the adolescent packages so they could, um, give input. Not what information was in there and what else they would like, or what wasn't very useful so that they could "***

D: "and would that sort of thing be really useful?"

N: "Yeah, I think it would be. If you had something in their lockers and when they arrive that told them about . But no, we have found peer and information folders that are in the, um, rooms and they have sort of, information like, welcome to the ward and ,um, health care team."

D: "more and more places are putting together information for themselves like that"

N: "yeah, and so these ones we've put together for our ward, for our families. But they are more..."

D: "for the parents?"

N: "yeah, they're more for the parents really."

patient questionnaire

surroundings

When I was first diagnosed with cancer at aged 12 I was in the childrens ward. It was colourful, it smelt nice and had a warm, friendly atmosphere. It wasn't stark and sterile. They had a cage of budgies in the ward, and it was so nice to wake up to the sound of chirping birds. Animals are great. Adults need the same encouraging surroundings as kids. I found it awful at age 17 when I relapsed being back in hospital and on the adults ward, where it feels lonely and cold. Adults have feelings too - we can't be brave all the time. Classical music in the day room?

The nurses let me put up my own pictures and cards

More posters

My surroundings are fine, there are things to look at but everything is calm.

new paint, paint there was mostly peeling off. A bright happy colour.

More variety in colour, each room could be different with less clinical scheming. Dayroom could be more inviting and modern.

Part of the ward to have more things for adolescents instead of always for younger kids videos for older kids.

Hospital smells unusual. The light isn't very good. Colours are dull.

I had a window view over town. Painting the walls- other than white or grey. Have murals or more paintings -Framed photos of nurses or doctors? Poetry or famous encouraging sayings on the walls. More info on notice boards. Purchase or get donated quilts for the beds- just to add colour. Bright, colourful curtains which separate the beds. e.g. the kids ward had clown curtains.

perhaps a section of photographs of people having a good time.

A larger encouragement for teenagers to bring in their own posters etc to feel more at home

sparetime activities

use the phone talk to people

wander around the ward in a wheelchair

I wrote a diary of what happened each day

talk to my friend, school room

talk to patient/nurse if not busy/needed

went to school at the hospital

I brought most of my entertainment from home

school work, just wondering around in a wheelchair trying to find some thing to do.

watched videos

had plenty of visitors and lots and lots of talking.

Talked to family, friends

approaching medical staff

The doctors and nurses are extremely friendly and are always willing to help you in any way.

But a couple of nurses very grumpy

They were very nice and co-operative

They were excellent, really really positive and approachable

They were all very nice and helpful.

I think some of them are easy to talk to but not all of them.

The Nurses and doctors are very kind, friendly, and approachable.

Easy to talk to, very patient, humorous

They're easy to talk to

Encouraged to ask if I needed anything

All nurses very nice and helpful

Not many questions were asked because I felt like I was kept informed

medical staff friendly/impersonal

depends on which staff

Extremely friendly Except for a couple of them.

It depends on what their personality

Really great people who helped make my illness as easy as possible

All very nice people.

Bit of both, though generally good.

people to talk to

My mum was with me everyday and night. My dad and brother visited every night, and plenty of close family friends visited. I didn't meet any other patients, on this particular stay.

I can talk to the people in my ward, the school teachers, my mum visits me everyday and my friends have been to visit me too.

Patients were around all the time chaplain mostly came once a day.

I had an extreme flow of visitors which I could talk to.

family

cultural needs

I think that they should sometimes speak their language (nurses) to make them feel comfortable, at ease

Wasn't really thinking about culture

I don't have much of a culture - so yes

no problemo's

hospital boring/interesting

(extremely boring) just sit around waiting for doctors.

(Boring) Couldn't do very much

(Very boring) I wasn't there by choice

(Boring) Staying in the ward all day.

(Very Boring) The hospital doesn't have the funding to interest the average teenager. (Play station etc)

(Boring) There is nothing really that you can do apart from go to school from 9am-3pm

(Boring) Nothing on TV, been reading too much. What else can I do when there is no-one here? there is nowhere to go.

(Very Boring) I was physically limited and was so drugged up I was unable to concentrate on anything.

(Neutral) I am used to visiting hospital so I know what to expect - some of the tests were interesting.

(Interesting) Learnt more about my condition and post operative continuation of treatment (ie anti-rejection tablets)

(Neutral) I've been asleep most of the time

(Extremely interesting) Nice nurses, fun stuff to do at the school

(Boring) I don't like it

(Extremely interesting) Being in theatre and the effects of the anaesthetics

(Very interesting) Meeting new people having new experiences

(very interesting) school, books

I couldn't really do much because I felt sick all the time

A new and different experience with everybody around and worried so much.

Having been in hospital a few times before, I knew what to expect.

feeling certain/uncertain

(certain) already know about my illness.

(uncertain) Nobody would tell me anything

(very certain) The staff told me everything I needed to know

(Extremely Certain) Dr's always explain what and why they are doing things.

(no R) I was pretty numb - it was all happening so fast -

(Uncertain) I was very nervous going up to theatre because I get very sick after operations.

(Certain) The doctor didn't even know because he had to open up and see, but he explained the main things really well.

(Extremely Uncertain) very emotional time for all concerned me, my donating Dad and Mum.

(Uncertain) This operation has never been done in NZ before

(Extremely uncertain) What's going to happen?

(very certain) I was told what was going to happen but on the odd occasion I would be told I was going to theatre earlier than I did.

(very certain) Doctors and Nurses told me what was happening to me - but a lot of the time I didn't know what time things were happening.

(very certain) The doctors were not really sure what I had, but they told me all the options.

I didn't like to ask questions because I didn't really want to know the answer

The prospect of having a killer illness (cancer) and the treatment I would have to undergo the most frightening experience of my life. However the staff were very helpful in giving me positive messages about what was going to happen.

informed about treatment

(extremely informed) Had plenty of previous admissions

(Very Informed) The doctor was very good at explaining everything.

(Informed) Doctors did not keep me informed always.

(Very Informed) I was well informed prior to being admitted about what was going to happen

(Very Informed) Doctors always explained treatment well.

(Very Informed) The dr's talked it over with me and told me how they would put me to sleep.

(Informed) I didn't always take on what they said but they told me what they were doing

(Very Informed) All my questions were answered

(Extremely informed) They went through detailed notes informing me of the treatment

(very informed) I didn't have much treatment, but was told about my operation.

(extremely informed) told everything that was happing to me.

I knew what was most likely to happen as a result of treatment and I knew everything I needed to know and my parents knew in more detail.

Most of the time I was informed, other times not told straightly

feelings being examined/treated

(Comfortable/Embarrassed) Sometimes OK sometimes I get ticklish and laugh.

(Comfortable) lumbar punch with a couple of drs including a trainee

(Comfortable) It was interesting, I learnt things I did not know about my anatomy.

(Neutral) Doctors and Nurses were impersonal while examining me

(Neutral) I've been in and out of hospitals so much I'm used to being looked at.

(Very Comfortable) My dr's are men. (13-14yr old fem)

(Neutral) I CAN'T REMEMBER MUCH

(Extremely embarrassed) I don't like it much

(Comfortable) When it comes to treatment I get scared

(comfortable) I was fine, I only had temperature taken etc

I don't like being seen throwing up and I hate being examined

there were some embarassing situatios but I was mostly comfortable since I knew it was all necessary to make me healthy again

I got used to people always asking about bowel movements.

feelings afraid/unafraid

(Afraid) how was my family going to cope at home

(unafraid) I just went with the flow - what happens, happens as long as its good

(Neutral) Before being operated on I was quite afraid. Most of the time I wished I wasn't there.

(Afraid) I become very lonely in hospital

(Unafraid) How afraid I was, was correlated to 1) the information I had 2) how sick I felt

(Unafraid) I just knew I was in good hands. I trusted the doctors.

(afraid) most of the time I was afraid of pain and not eating and stuff.

(afraid) I'd never had an operation before, and all of a sudden I'm HAVING "MAJOR CARDIAC SURGERY"

(no R) None of the above but I feel upset sometimes

(neutral) I wasn't comfortable about seeing other kids that were hurt.

(afraid) I was scared about my operation and what was going to happen

Not knowing if its all worth it, the treatment that is,

Cancer was very frighening at first as it made me contemplate my mortality. However after the initial shock I wa always knew that I would survive and my worst fear was needles. (I think I have a small needle phobia)

I was in denial a tad. I didn't really realise full implications.

experience of pain

My mum was allowed to stay but I didn't need her all the time

I hate having to come to hospital

(comfortable) It was a learning experience as well as a healing one.

(neutral) Staff and surroundings did not make me feel comfortable.

(very painful) Physically and emotionally I was in a lot of pain

(neutral) Except that it was really boring

(neutral) It was hospital

(comfortable/extremely painful) Extremely painful on a physical level and emotionally comfortable on a more emotional level with the staff as they were really wonderful.

(neutral) I GET PAIN RELIEF WHEN I NEED IT

(extremely painful) Just the pain that I have

(very comfortable) overly I think it was good

(comfortable/painful) when I was in pain I was given medication so most of the time I was comfortable

Although I was sometimes in pain, mostly I just felt very tired. Again, I can only praise the hospital staff for doing everything they could to make me as comfortable as possible.

other comments

Like having syringes full of H2O to squirt at people.

I went for a CT scan and the guy put some contrast dye into my leur, and then I stopped breathing and the O2 mask couldn't reach me. It was scaring the hell out of me

Most of my friends who were patients passed away which left me feeling quite afraid/upset/scared

grumpy, fed up, frustrated. when the physio said a time she would come and didn't come.

There is not enough to do.

I think its important for staff to know how important their attitude towards patients influences how they feel. An old, paint coming off, tired environment in wards makes patients feel even worse.

I felt very isolated - yet I wanted my privacy. I was thankfully given my own room during my entire stay which I really appreciated.

Doctors were good at explaining what treatment I have. Medical staff in general were friendly.

The nurses were lovely and they became my friends. Sometimes I felt lonely and trapped, I couldn't go anywhere or get fresh air. I got bored from time to time but they found things for me to do.

The morphine was making me vomit so I told the nurse (in ICU) I didn't want it any more but she just gave it to me and I was sick. The doctors later told me she wouldn't be my nurse again as I've got a right to refuse medicines

I think doctors and nurses should be easy to talk to. - Simpler words so I can understand.

Very helpful people

Not having anyone my age to talk to in the day stay building was hard

Having lots of friends and especially family nearby. Its had to imagine how important it is to see friends and family until you've been in hospital for a long period of time. For comfort as well as to know that there are people out there who really care for you.

I was a bit sorry to leave, I enjoyed some of the nurses. It was nice to have friends and family attention for a short time. Interesting to see how other people reacted to being in hospital - dealing with their situation and pain - in an odd social arena. Interesting social experience to watch other people, and get to know them.

advice to others

Dont be afraid to ask questions. "TV is not the devil"!! (Told by a nurse in the middle of the night.) that it was.

Just to do something to keep your mind off things. example play games or go on to the internet.

Think positive. Tell the nurses when your in pain, don't leave it to the last minute. Ask questions to doctors/nurses about the operation/tests etc. Let the nursing staff know if you have any special needs.

Have a TV and earphones, pack of biscuits fruit, some form of divisional therapy own pillow, depends on length of stay

take some comforts from home if your stay is long, mine was over a month. Home comforts make you the patient feel like a real person

Always look on the bright side of things. You'll be home soon enough. Keep the patient informed / what's going to happen / work them through the healing process. For serious illness or injury: Get them in touch with someone who has been through the ordeal, to help them through it.

Always ask questions if you are unsure of anything. Always make your needs known -staff can't help you if they don't know that there is a problem.

Feel free to ask staff questions, so you feel that your informed. Try to be positive. Know they you won't be there forever. Make the most of the rest. Write to family. Think of better times.

Talking laughing and crying help tremendously. Don't bottle anything up.

Just go with the flow. Most of the nurses and doctors are nice. Remember doctors have gone to medical school and they know everything.

Try to get well soon and get out of here as soon as poss.

You will get better. Be Brave KIA KAHA!

Everyone's really friendly, helpful and cares about you. And will help you with anything you ask.

Hospital bag contents: Clothes - so you don't have to be in pjs all day. TV if you can borrow one. Walkman If you can borrow one. Tapes. Books. Snackfood. Teddybear. Pictures and photos. Tissues. Be yourself - don't try to be too brave but don't give into pain and stuff, laughter is the best medicine! Let yourself rest when tired.

"You can get through this, be brave and be strong. I know you have it in you to beat this" -Those words worked for me.

Always be positive. If you believe you can defeat or overcome your illness you're already halfway there. I als encourage plenty of relaxation and as little external stress, ie other than hospital and medical care, as possible. Try to stay happy, if you want something, ask the staff, in my experience they will do their best to get it for you if any friends or family cannot. Always, always be as happy as possible. Look at the bright side however small it may be.

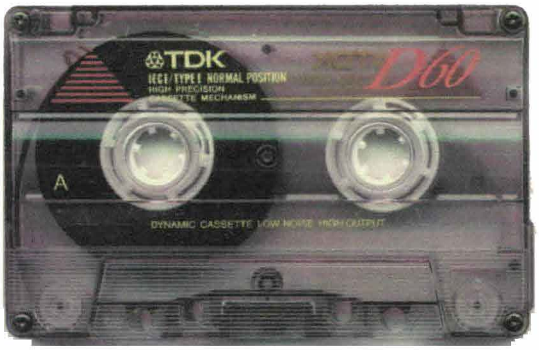
'I know this is a children's ward but they should have more things for people around 16 to do too. I mean they have heaps for kids under 10 to do, but over 10 practically nothing.'

16 Staff Interviews

for the design and
evaluation of a

Patient Information Manual

These Transcripts Support
a Practice-Based Research Project
for the fulfilment of a
Master of Design Degree
College of Design, Fine Arts and Music
Massey University, Wellington



2000
Glenna Duthie

These transcribed interviews between the Designer (D) and Hospital Staff were used to inform the design of the PIM. The questions the Hospital Staff were asked are highlighted in bold. These questions were:

> Can you describe any problems or challenges that you have encountered in dealing with adolescent patients?
>
> Can you describe any information, concepts or ideas that you have found successful in helping patients with any of the problems they face?
>
> Are you aware of any publication, resources, or activities that have been designed to help patients, particularly adolescent patients while in hospital?
>
> Have you any suggestions of what you think would be helpful to include in a resource for adolescent patients?

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D: "so can you describe any problems or challenges that you have encountered in dealing with adolescent patients?"

C1: "they get bored."

C2: "and isolation it's probably from their peers"

D: "is their behaviour any different from adult patients or more difficult to deal with?"

C1: "they can tend to act up at times and be rather childish."

C3: "and they're worse when their friends are around. It's just adolescents really [laughter] acting up at times."

C1: "Mmmm Mmmm."

C2: "Mmmm Mmmm."

D: "when I began looking at the problem I thought that there was various things that could cause problems in hospital, one of which was the system itself, and things to do with the immediate environment, actually being in hospital, does that bring to mind any thought?"

C1: "like being in a cubicle with four other patients?"

C3: "varying in age groups"

C1: "with judging what's wrong"

C2: "we try to address that if we can, but often, sometimes we can't. I think probably the main thing is the isolation, in that for them to actually be in hospital is removing them from their peers and from what is normal and so therefore that, in itself, is the big issue because they don't want to loose face in their peer group. So if you're not there you loose, um, a spot in that group and that's their fear. Is that even though its often ungrounded - like th their obligations, and how they can, you know, get a fair treatment while they're in hospital. Their friends are often the opposite and actually fuss around them, they think they're going to lose their place and so they are very scared of being removed."

C1: "and they work hard on maintaining their identity. Dressing in their own clothes and lots of stuff they bring in from home"

D: "could you tell me a little more about that, the kind of things that you have seen on the wards?"

C1: "they take in duvets and sheets"

C3: "pillows"

C3: "cuddly toys, books"

C1: " Posters Yep"

D: "Does that cause a problem?"

C123: " No, No It's great "

C3: "I'd say we try to put a person, if they were in for a long time, someone like that in a single room, so they can take in their things and make it their room. so it's more like home."

C2: "whereas an adult as such, would bring in a pillow. They wouldn't worry about all those other things. And they'd only bring their pillow if they weren't really sick. Wouldn't they? I mean they wouldn't think about it if they were acutely ill? They'd just so relieved to be here."

D: "while we're talking about that, perhaps it would be good if you could give me a basic idea as to how many adolescent patients you might have on your ward in a year."

C123: [laughter]

D: "Or during two years or...?"

C123: "Mmm [tut tut]"

D: "Would it be one or two, or would it be half a dozen?"

C3: "We could count one hand"

C2: "under ten"

C3: "it would be under ten"

C2: "in this ward"

C3: "in this ward"

C2: "but more in your ward wouldn't there be?"

C1: "Yeah, because we have a few people who have got cystic fibrosis who would be under twenty who would come in - the same people maybe three times a year"

D: "OK. so they're sort of what? More regular?"

C1: "Yeah"

D: "So, do you find that different?"

C1: "That's a whole different thing because they have different body issues, life span issues that are so different from other people, other teens"

C2: "and they also know the system really well"

C3: "and they know the system, and they know the hospital, and they've been in and out, since they've been kids and they have that change when they become teenagers. They don't go to children's any more, they come to the adult ward. So that's a big difference too is the fact that they leave that very safe haven of the children's ward"

C2: "and into the big bad adult wards"

D: "Do you get to know them quite personally?"

C123: "Yeah"

D: "The second question I had was if you could describe any concepts ideas that you have found successful in helping patients and I was thinking more broadly with maybe things like pain, and why me? or some of the more psychological issues that they might face "

C2: "I think you have to take that on a very individual basis because each person copes in different ways. And I think its more, with the adolescents we've had, its been more making sure that they understand. Because often they meet, like a doctor could tell them what is wrong with them, and *its something quite serious, but the next breath they want to know if they can go and buy fish and chips in Newtown. And so actually it's probably the communication is the biggest issue.*

I was just thinking about that girl we had with Malitis, there were some major issues going on with your body and it had been explained to her but she just wasn't "

C3: " taking it in "

C2: " taking it in "

D: "So that's quite a common problem? I guess that it would be quite hard to work out sometimes whether a patient is taking it in or not"

C2: "Mmm"

C3: "Yes it is"

C1: "Yes I think people, kids, whatever you want to call them, can often be more in denial really."

C3: "Mmm, and quite often the things that they get can be quite acute and so they haven't had time to prepare. Or they may have been quite well the day before, or the week before and suddenly what they think is the flu is actually something much more serious"

[interruption someone at the door]

*D: **"What about any other resources or activities that you may have seen or resources that people use on the ward, books or activities or ?"***

C123: "Not really, No there seems to be a terrible lack. No an absolute lack. A terrible lack of things, I haven't seen anything."

C2: "I mean, basically we have jigsaws or we suggest that they bring in things themselves from home."

C1: "Upstairs, the cystic fibrosis patients, someone bequeathed them some Game Boys to be used by those patients"

D: "Oh OK."

[interruption someone at the door]

C1: "You know the one about the psychological things, something about the same nurse looking after these people. This would probably be something to. "

D: "And that doesn't' happen?"

C2: "We would probably try?"

C1: "Yeah they would probably try"

C2: "Its just more continuity of nursing care"

C1: "so you get better relations"

C2: "Right"

[interruption someone at the door]

D: "I figured that although doctors are supposed to give the information that they need to use and *stuff, but that you nurses were more critical to what was happening?"*

C1: "Mmmm "

D: "Do you think that a resource would be useful, or games and activities would be useful?"

C123: "Mmm, Definitely, Yep"

D: ***"And do you have any ideas as to what that resource could be or what you might find useful or want to include?"***

C2: "I think the idea of something that has games in it is a good idea, but I think also something that gives them the confidence to actually ask questions or explain to everyone else in the ward how the system works would be quite good so they understand, cause they often like make friends with the younger doctors or nurses and then when they... the more senior doctors who are the bosses come along "

C3: "the consultants"

C2: "the consultants and makes a decision they don't understand who he is or why because they've become friendly with the people that they see everyday. And so maybe how the system works."

C3: "the different levels of doctors or something."

C2: "and how to question, how to actually question those people."

D: "OK. Would it be possible to make a resource that would work across the wards that did that? I mean the levels of doctors and nurses are fairly consistent across all the wards."

C123: "Yep they are"

C3: "OK. That would be good."

D: "Is there anything else that you ?"

C: "I think that sort of resource would be good to give to everyone. Some of those issues actually they're not just adolescent issues."

C123: [general agreement]

C1: "For you to target them you really need to find some "

C2: "Some issues that they have really."

C123: [general agreement]

C3: "adolescent issues."

C1: "Because everyone that comes to hospital can be very lost by those things."

C3: "and not understand the system either."

[pause]

C2: "But I think that a lot of older people have come across it before. Whereas adolescent patients haven't, and they haven't learnt how to question. Whereas, [pause] what would be useful You see, the whole way that we our day is structured is often against what a teenager wants because for example "

C3: "Early in the morning"

[laughter]

C2: "We have dinner at quarter to six at night"

C3: "Breakfast is at eight o'clock in the morning and, you know, comes at quarter after eight. I mean, half the time, the last thing they want to do is eat breakfast then they want to wait until ten."

C2: "ten"

D: "Do you get resistance? Do you find resistance?"

C3: "Well we just adapt."

C2: "We let them sleep and wake them up later and those sorts of things. Do those sorts of things"

C1: "We've got an eighteen year old upstairs that won't even talk to you till after eleven."

C3: "Ohhhhhhh"

D: "That must be quite difficult in hospital because a lot of things happen in the morning."

C3: "Mmm, it is. That is where it becomes difficult. That's where you have that struggle going on.

C2: "Yes" [laughter]

C3: "The routine interrupted, taking tablets" [laughter]

C2: "It would be quite nice to come up with . Well a lot of patients unfortunately, well fortunately for them, apart from the ones "

D: " are very short term?"

C2: " very short term. So it's really little measures really. Unless we get someone whose in longer term with cystic fibrosis, or even the trend these days is that even someone whose got say bacterial endocarditis might be in for a week or two. But then the chances are they would then go home and be treated at home."

C3: "by a district nurse"

C2: "by a district nurses now. Because the trend is really away from hospitals."

C3: "They'll be treated at home and they'll be having their IV antibiotics at home. But they still need to be in a role that's looking after themselves. They've been given freedom they need to "

C3: "limit"

C1: "respect that they're still sick. That they need to "

D: "even though they're not in hospital."

C3: "That's right, yeah, they've still got to sort of remember that they're "

C1: "They expect too much of themselves."

D: "So would it be useful to have something in the booklet that helps bridge people from being in hospital to going home?"

C123: "Mmm That would be really good."

C1: "and some people need permission to slow down and rest."

C2: "Well it's not cool."

N: 'Yep. All right? ***So any problems.*** *The problems are that they, they have their own needs. One of them is, they like to keep up with the latest and greatest in terms of music and stuff, so they like playing it loud. They like watching TV all night. Currently the facilities are such that we don't provide for that sort of need, based on the fact that they're sharing 4 bedded rooms. And they often have a sick kid in there which does need to sleep when they're trying to play it loud. And also the loud music can be quite destructive for the rest of the ward.'*

D: 'but the music and videos is something that you supply or that they bring in?'

N: 'Both, we've got portable stereo systems, we've got VCRs attached to TVs that are portable. And we've also got a fixed TV in the rooms. So some of the younger staff bring in tapes for them to listen to. But the kids, if they've got access to tapes in the community, bring them in for themselves as well. Especially in the long termers. You don't have problems with the short termers cause they're generally sick. They spend a day in recovery and they're out. Um, its your long termers that are often sick for a couple of days- three or four days. They come well quickly, but they need to stay in hospital for a longer treatment. And its when they're well that the hospital system starts wearing a bit thin with them. And that's when they start exhibiting deviant behaviour. Yeah, and its to be expected. Like we do expect it. Adolescents being adolescents, they get bored. They get cheeky. You know, they tend to come from a wide variety of backgrounds. You know, a lot of our adolescents are street kids. You know, that's the smoking and playing with meths and that, and like cigarettes and petrol, and that tends to burn them. So its very difficult to provide any entertainment or any sort of discipline or anything like that, that a street kid hasn't heard or seen before and knows exactly how to sort of manipulate, and ignore and basically go ahead and do their own sort of behaviour anyway. Because adolescents, their peers are really important. You tend to get adolescents who come from good homes and their parents aren't in hospital with them. The adolescents who have got decent behaviour will actually very quickly change their behaviour to match the new kid on the block, which might be a street kid or something like that. So that that's your problem. And that has upset a lot of adolescents. Adolescents who are from homes where the adolescents is under control, parents get very upset very quickly because their kids start using abusive language and coming up with terms that they're not allowed to (use) in the home and things like that. So parents can become quite distraught from that. But because we can't separate them out, (we don't have enough side rooms), its very difficult to segregate them. So what else?, no, that probably covers (question) one.'

D: 'Yep'

*N: '****OK, concepts and ideas.*** *Um, reward for good behaviour still works. We have had several adolescents that have been street kids that have come in refusing, saying that they're not going to go to school, that they don't want TV that they don't want anything. What I have been known to do is negotiate with them the minute they hit the ward, and say what is it you want? Is there anything that you want that I can actually provide? Sometimes it might be a playstation. More often than not, its actually access to a single room. So, I decide what's most important for me. So in terms of a burn kid what's most important for me is that they actually have a daily dressing, so I will negotiate with them that, in order for them to keep their side room as long as they want, they have to go ahead and have a daily burns dressing. And they can pick the time. But, in order to keep* *their side room, that's the only thing that they have. And then what I have done in the past is, I have given them the side room and I have thrown like- a playstation into their room and a VCR into their room, even though they've said, Ooh they don't want it, (they're too tough for that) given them full access to that and then withdrawn it, the VCR and the, um, Playstation over the next couple of days. And they, in fact, come to me and say, no, we want that. And if they want that, then they have to negotiate further with me some better behaviour.'*

D: 'So it's sort of saving face on both sides?'

N: 'Yeah, it is, and they negotiate the rules. And if I can live with the rules, then that's them keeping their tough side intact, and me actually getting what I need out of them. Because, ultimately, you know, if they don't go to the school in the community, there is not point me banging my head against the wall trying to get them to school in the hospital. Because, you know, its not going to happen. But there are some things that I need to get them to do, like have treatments, or take medication and stuff. And its up to me to negotiate as much as I can, because ultimately they'll still go ahead and do, you know, they'll do what they want to do, and, you know, if they think they're losing face, they will actually choose not to have a treatment just to make you pay as an adult. That's just their mind. So you do need to negotiate. What else? Um, oh somertimes they let a couple of responsible teenagers have access to the play room when everyone else isn't allowed access to it. Which they deem as being quite responsible and quite mature. So that works. Again, if you get the right combinations of adolescents, you can actually let them have the TV on a bit longer, let them stay up a bit longer, and again that's negotiated. And that's worked on a terms of good behaviour which they do respond to. That, um, I think its really important for adolescents that they don't look at the same four walls all day, I'm really keen that they don't have free access to just what they want 24 hours a day because they become bored. It just becomes their routine and therefore they get bored with that. Therefore, even that doesn't work any more. So its important that either they stay in their rooms, on their beds, doing a bit of school work or whatever, and then you actually move them into a different room, like the playroom (what ever you want to call it) and that gives them a variety of rooms to look at. And that keeps them in a routine. And also it means that they don't get bored with the one environment.'

D: 'You have one playroom for this ward?'

N: 'No, we share with that middle one. But it means that if they stay in their beds till three and then what happens is that room then becomes like an older area. And they can put pool and that. And that means that they can either, stay in their bed ,or stay in the school room and then move to that room in the afternoon which I find better than just letting them have access to that room all day. Because then, it just becomes 'old hat' and so they start nicking wheel chairs and disappearing off down corridors and stuff. Um, I find...'

*D: **'Are you aware of any publications or anything?'***

N: 'No I am not aware of any publications or anything. Basically its just behaviour modification as a part of psychology, is all that I've read on things like that.'

D: 'What about any information that you give to the patient on the ward? Do you give them any information about the ward routines?'

N: 'We've got a welcome to ward 2 sort of routine. Its no more beneficial for adolescents than it is *for parents. So, its not additional to what we've got, um a resource for adolescent patient. Its all about resources. Resources are good as long as it is what they want at that particular time. You know adolescents think that play stations are really cool, so that's play resources. Um, in terms of written, I mean audiotapes are really cool, um, its very much you've got to meet what they are getting out in the community, or what their needs are in the community. Other than that, I'm not sure. I mean, sometimes, sometimes your on the border-line. I mean you educate them like an adult but they still have quite a childlike impression of what you're trying to tell them, which can be quite detrimental. Um, so its quite important to gauge what sort of level they're working at before you start. But, you know, I don't have a clue there.'*

nurse-adults' ward

Comments: ***extremely busy, noisy ward, people arriving and being discharged constantly***

D: "I guess the first thing is, how many, do you know how many teenagers there would be on the ward, on your ward typically?"

N: "Well, often not many. Probably one a week maybe, if even that. At the moment we've got one he's 18 years old, it's very rare."

D: " and how long would they be staying for?"

N: "Usually its only about 3 days (on average) because if they come in, and they're that young, its just that they've probably just broken an ankle."

D: "In that case, I guess we could just start running through the questions."

N: "Can you describe any problems or challenges that you have encountered in dealing with adolescent patients. Boredom. Complete and utter boredom. That's the major problem. Mainly that's with the 13-16 year olds and they're just unbelievably bored."

D: "Do they do anything? do they just look bored or do they actively do things?"

N: "They don't actively do anything. You've actually got to go and find something for them to do because, on this ward, we don't have anything of that sort for adolescent people. We say, "here, have a magazine". But that doesn't keep boys occupied. It would maybe keep a female occupied, and it's mainly males that are so bored. And they want to get up and walk around. And trying to find something for them to do . There's the kid's ward, and we often ring them with the 13-15 year olds and say "please come up and have a look at them and get them to do something".

D: "and does that work quite well?"

N: "It does, it does. Some of them, the things they get them to do are just a little too young for them. Cause they bring in all sorts of things like colouring books. But that's just a little bit too young for a thirteen-year-old. But I think that adolescent age is where does it start? 15 and up?"

D: "Mmm that'd be right."

N: "Understanding, they can be better than adults sometimes. They're great. It's just the boredom. Um can you describe any information, concepts or ideas that you have found successful. Um, yeah just the children's ward, getting them up works reasonably well."

D: "I was noticing that you have an information book about the ward. Not every ward's got that have they, or?"

N: "No, we made that specifically for this ward. And other wards I've been to I haven't seen that"

D: "and you give that out to the patients as they come in?"

N: [nod]

D: "That's a really excellent idea."

N: "Its great."

D: "It actually covers a lot of the problems that I thought could be included, like knowing your rights and all that sort of stuff"

N: "Yeah, yeah its good for kids because "

D: "and pain relief?"

N: "Yeah exactly. Because they have no idea how to use a bell, or what its for, and you could spend an hour with a person trying to teach them everything because That is a great problem actually because um."

[interruption]

N: "we get a couple of scoliosis patients in and they're quite young, say between 9 and 13, and their problem is wanting their mother. And if they don't have their mother they will put their hand on the bell every five minutes, literally"

D: "So they obviously feel quite afraid."

N: "absolutely, yeah. And if their parents can't be there they expect us to be there. And we can't be there because we have three other patients to look after and that's a major, major problem."

D: "Is that because they're in rooms by themselves or?"

N: "Yep, yep. When they...well actually they don't eventually go into a four bed room because they are so young and their parents often stay over, when they decide that they're ok. and they're not going to stay over, they're just hand on the bell"

D: "If you could imagine something that could be given to adolescent patients to help them through being in hospital, does anything come to mind, would it be games based, or activities based or information?"

N: "Not information, I think they'd die of boredom. Activities and games I think. Even one of those little game master things, they could occupy a teenager for hours and hours, but they often don't have them. Parents don't have them. TV's, but that's the same, it costs heaps of money."

D: "Do you have a room in here for patients, or a place to store activities?"

N: "That could be a good thing, actually. A big activities room, but whether it would get used."

D: "Most of the people are stuck in bed with the plaster and stuff?"

N: "Yeah, and they can't get out of these rooms to go and do anything. So the activities they do have, would have, would have to be tiny, and just sort of be writing or paperwork or something"

D: "Anything else?"

N: "Not that I can think of at the moment."

D: "You have treated a number of teenage patients. Do any of them spring to mind? They are not in for very long though, are they? So they would not have time to take in stuff, or change their environment or anything like that?"

N: "The longest they'd be in for is about five days. And after the first day they're all, my goodness this is so new! and 'that's fine'. The second and third day they're sort of, that's when they start to get bored. You just can't get to them to entertain them."

D: "What about pain relief? Do you have any problems with adolescents with that?"

N: "Kids no. It's when they start getting 20 and above that they start screaming. But kids, they don't have. When they have got pain they're not going to scream like an adult. They're great"

N: "find that kids between 13 and 15 don't listen properly. You tell them something over and over and over again and it doesn't go in. Like with the bell. "Don't ring your bell every five minutes!" Five minutes later they ring their bell. You just can't get through to them. But 16 and above, fine."

nurse-childrens' ward

*D: "**Can you describe any problems or challenges that you have encountered in dealing with adolescent patients?"***

N: "Um, Communications is a big one. But I'm also a teacher in NLP neuro-linguistic programming, so I have no problem communicating. The biggest problem/challenge we do have is finding appropriate work for rheumatic adolescent children, and appropriate work and diagrams to illustrate their infections and their problems."

D: "Is this because there is none available?"

N: "Because the ones that are available are inappropriate, they were written a long time ago and they don't meet clinical standards. So at the moment we are trying to design a new chart for the rheumatic fever children, which we've no idea how to do."

D: "Is it because the illustrations are outdated or because they are inaccurate?"

N: "Because the illustrations are quite horrendous. One is a bug - a streptococcal bug - with its finger in one ear and coming right out the other ear. It has big feet that look like something out of a horror movie, actually quite off-putting and frightening for children to think that they have this thing inside them that is alien. What we're trying to do is make it more correct in terms of more culturally appropriate, more aesthetic, and less frightening especially for adolescence who interpret things so vividly. So we're trying to make it much softer and a lot more fun. That's one thing were trying to design at the moment."

*D: **Any information, concepts or ideas that you have found successful in helping patients with any problems they face?"***

N: Yep, due to the neuro-linguistic programming course, you can actually use diversional therapy. The play specialists use diversional therapy when putting in intravenous lines etc etc. It's very, very effective. We actually talk them through it, talk them down out of situations they're in, especially aggressive states. Their concepts and principles are very, very good image-forming internal representations."

D: "Is that all from the school of thought called Neuro-linguistics?"

N: "Neuro-linguistic programming - it's how you communicate to people and what you communicate to illicit the right response."

D: "It's mainly for verbal interactions?"

N: "No, its kinaesthetic as well as audio visual. You can actually see that what I actually say to you today as you sit here has a direct effect on you. It is based on the principle that you cannot not communicate, ok so that's what it's based on.

*D: **Can you think of any publications resources or activities that have been designed to help patients particularly adolescent patients on the ward?***

N: Not at the moment while I sit here. I cannot think of any resource packages that are in psychiatry that help children with their adolescent problems. Although there is a doctor here that is very good with adolescent patients and adolescent clinics um."

N: "he deals with them. Activities, we devise our own activities based on a sharing principle and a development principle as to how they are actually going to progress to the next stage while they have some autonomy and self direction."

[interruption person comes into the room]

*D: "**Have you any suggestions as to what may be helpful for a resource?**"*

N: I think if you go and work with adolescents, and actually stay with them, and actually watch how they communicate, you could actually divulge a lot from it. But you have to look at trends with adolescence. You have to get the trend for the moment, the in things to do and one thing or another, then you'll learn a lot by talking to them. If you don't talk to them and find nothing out, then you start mind reading and suppose what they want."

"I think its a good idea what your doing, but I'd like to see how your going to design it or what your going to design, is it a picture is it words is it what?"

D: "Well I'm hoping to learn from talking to different people. But what I have in mind, what I initially had in mind, is a mix between hospital journals for young children (where they can draw and write but that also gives them some information about the hospital), and adult books which basically give people information about how to make the best out of their hospital experience. So I was thinking somewhere between the two but with some sort of maybe game component to it."

N: "We are actually designing a rheumatic fever protocol and policy, and as part of that were putting word games in it for the older children because the younger children were going to develop some other things as well. It's transcending the age gap which is the problem. You'd have to have different sets of manuals for different age groups, but no it is a good idea and I would like to see it when its done."

D: "So the stuff that you are designing will be just about rheumatic fever?"

N: "It will be"

D: "Because another component I thought I could have in the manual was a basic body diagram like you have."

N: "We have done, we have books already though on body parts and we go through them with the children depending on their receptiveness and their state of mind at the time. We also use the play specialists to actually implement them a lot we don't have the time as nurses to do it and they're excellent at it they sit down and talk to them about it"

D: "Part of the reason that I'm doing this project as well is for the adolescents stuck on the adult wards, who don't get the sort of facilities that you get here."

N: "Yeah, I totally agree with you. Ah, 15 to say 19 year olds, 20 year olds even, who've had to go up there do get the rough end of the deal being stuck with a lot older patients. This can be very difficult, especially with females. It's very difficult I think in the late age group for females and males who want to interact than sit around and watch a whole lot of old chaps cough their guts up. Basically we do offer more than they do up there. We do have the odd 16 or 17 year old down here who can't cope mentally with the stress on the medical wards."

D: "Anything else that you'd like to add?"

N: "No I think its a wonderful idea and when you've done it and you've passed it you can come and help us with the rheumatic fever one."

charge nurse - adults' ward

D: "Firstly, and I talked to you on the phone about it, but how many adolescent patients do you have?"

C: "We probably have one or two admitted a year"

D: "and how long would they be staying for?"

C: "Ah it varies. Sometimes a couple of days, sometimes a couple of weeks. Generally, it very much depends, some of our younger adolescents we'd put in the children's ward if at all possible. But if they need specialised renal nursing care that's quite intensive renal nursing care, then they'd come here. But it very much depends on their maturity. I mean the ones we've had recently have been transplant patients. We don't send them to paediatrics to look after if they've just had a transplant. they're sort of the ones that do need the nursing care."

D: "do you get repeat, ah...."

C: "admissions? Yep, yep we'll get the same ones that do come back with complications later. But once again it depends on the adolescents I can think of have been probably under 16 mostly and so if possible we get them in the paediatric ward"

D: "ok. Can you describe any...."

*C: **"problems or challenges?** I guess its, from our point of view, m because were not geared. I'm thinking of the younger adolescent group. We're not geared to looking after that group of patients. So the challenges are remembering to get that involvement with the parents and stuff like that. Knowing when to get parent's consent and when not to. This whole thing of privacy. You know, trying to negotiate what you tell the parents and what you don't. Trying to decide whether that kid is actually capable of making adult choices. And sometimes they are and sometimes they aren't. And it depends on the extent of it. We've also had kids that maybe their parents haven't been able to be there with them - from out of town. Maybe 14 year olds or something like that who..."*

D: "What do you do in those sorts of situations? Does someone work as their guardian?"

C: "No, no, it depends on the situation. We can sometimes get, like if its something that requires written consent, we might get other doctors to sign it. But a child can actually give consent in some situations. But that's the thing, its judging, do they really understand. But most times you get to know them well enough to know if they've got that level of maturity to actually be making those decisions, and we decide. Then decide what they're getting into and does it really need parental evolvement. We always run it past the parents anyway and ask for their verbal consent as well for things. So it's that sort of judging the level of maturity. In some ways they can be very mature and in other ways very naïve I suppose. The other challenges are to do with the whole control thing and the sort of acting out that you get. And that's something too that some of us are more experienced at than others not. That there are some that are very good at dealing with adolescents and some that would [hiss, sign of the cross] back away from them and don't want anything to do with them, which is quite understandable."

D: "Acting out in what way?"

C: [sigh] "Ah just either threatening type behaviour like 'well I just won't do it, I'm not going to do it and I don't care what happens, I don't care if I die, I don't care!' You know that sort of stuff, like either not taking pills or not doing something. Sometimes being a wee bit woozy, maybe. like um.."

D: "like injections?"

C: "Errrorr or things that involve pain, things like trying to get people out of bed, up and about and mobilising after an operation. Yes it is going to hurt a little bit and we do provide pain relief, but they do have to put up with a little bit of pain. Usually, its going to be a wee bit uncomfortable getting out of bed. And the sort of just downright refusal. When you sort of, when you want to grab them, and it's often, its not being able to reason with them at times. But it's not all the times. Sometimes really good, sometimes really bad. So there's sort of that inconsistency. Also, knowing, especially when you have kids, that have had a chronic illness (which is mainly what we deal with), knowing to what extent to get the parents involved in that. Because you also know that it must be very hard on them having a child with a chronic illness and manipulation is often a lot worse with the parents than it is with us. It's hard to know when you're being manipulated as well. And it's for real because sometimes they make things out to be really dire when it's not. And knowing how much to actually ask the parents to put their foot down. 'You tell your child' Because sometimes they need to be told that you have to do this because they're not actually able to make those decisions for themselves yet. And they can be really horrible to their parents too when they're unwell. And you're sort of caught in the middle of it a little bit. And you want to protect the parents from the child's bad behaviour. But you are also thinking 'is it my job to be telling the kid what to do? Its sort of the parent's job" but you know that it causes all sorts of problems."

D: "Is it mainly to do with issues of pain or operation or....."

C: "Yeah just everything around treatment. It seems to be like them trying to get a bit of control. And so its not sort of one thing in particular, its like normally with a patient we sort of negotiate their care and you say, 'look this is what we think it would be good for you to do' and you plan the care together and you explain why you think it would be good and all that sort of stuff. And you *come up with a plan and its going to be best for them all round. Well you can do that on one day with a teenager, the next day they say, well I'm not! You know one day its quite reasonable to have a shower in the morning shift when we've got more staff on that could maybe help, you know, if they do need assistance and they say 'I'm not having it, I'm not having it!' and you say 'well that's fine you don't have to have a shower today' but I want it in the afternoon or, I want it at 2 o'clock and it seems its not anything to do with the shower, its to do with the control"*

D: "Mood"

C: "Yeah the mood and the control and the putting your foot down and don't boss me around sort of thing. I suppose its just the different levels of maturity and trying to then negotiate care around that can be quite sort of frustrating. Sometimes, especially when its 'I don't want that doctor in here, I don't like him'. It's like trying to explain why and that sort of stuff. You want to say 'grow up' right, But you can't really"

D: "You don't have much choice with that sort of thing though do you?"

C: "Well, yeah you do have a choice you see. And that's the difficult thing, you see. If the parents not right there, you do have a choice. Anyone can say ' I don't want to have anything to do with that person and the thing is, if that's actually going to compromise your care because that is the best person to see them. You know, they might be a specialist, or something like that, then trying to explain to them that but them not responding to reason, and getting more and more shitty. And then getting more and more wound up and then sulking because they realise that they know you're right. But they're not going to back down and say' that oh OK' we'll do it your way. So it just becomes a big sulk and yeah. So it's difficult because they don't want to admit that they're wrong or that they over reacted or something like that. So that's the way it seems anyway"

D: ***"Any information, concepts ideas that you have found useful?"***

C: "I guess the control thing is letting or making sure that they do have it, a say in decision making. That they do have control over things. Maybe pointing out the things that they do have control over and also just acknowledging that often when they are seeming (to be)manipulative or unreasonable they are often scared. And often that manipulation becomes a habit with people, and adults as well and I suppose its "

D: "slightly more noticeable with teenagers"

C: "I think so, because they can't disguise it. They're not as good at disguising it. So yeah, it's a little bit more obvious. I mean, I suppose its realising that sometimes they do need to be treated like an adult, and sometimes they need to be treated like a kid. So sometimes they need a 'there, there' and a hug and a crying sort of thing and other times they need to be making their own decisions so "

[interruption phone]

C: "I find that there are particular nurses that are better to look after people. We've got some older nurses who have gone through looking after teenagers and they just seem to know. And also whether its maybe response to authority or something that they see an older nurse as a sort of authority figure rather than a young nurse 'who are you to tell me what to do?' cause that's often how they seem to perceive it."

*D: **"Do you know of any activities, resources or do you know of anything on the wards"***

C: "No nothing in particular we're sort of aware of for the younger ones. Sometimes getting them involved in some of the activities that are going on in the paediatric department and getting the teachers involved. But nothing specifically in our ward. We're thinking we get donations from time to time and what we should use them for. And we thought that a play station might be a good thing. Just something that actually keeps them occupied because they get so bored. Because you can only read for so long and that sort of thing"

D: "But you don't have anything "

C: "No, we don't have anything specific aimed at adolescents, No."

*D: "Any. I guess that's your **suggestion** there, the game boys."*

C: "Well yeah, Playstation, something that actually fills in the time, um, yeah. I can't think of anything else unless there was a person who could co ordinate activities amongst several adolescents, but then it's sort of "

D: "Its not enough to warrant it?"

C: "and its not like a kids thing where you can bung a whole pile of kids in together and do an activity together. Adolescents are like, well I don't want to be doing things with that dork, or that other, and they don't want to be labelled even as sick or even as an adolescent. You know its like I am my own person and I don't want to be dumped in with, and have activities with, a whole lot of other people. So I can't think of, yeah, except something that keeps "

D: "that keeps them occupied?"

C: "Yeah 'computery' type stuff seems to be what people are into. So yeah, yeah no I can't think of anything."

D: "Anything else that sort of springs to mind about adolescent patients?"

C: "Ah no I suppose I personally find them difficult, because I don't have that experience. I don't have kids and I don't have dealings with a lot of adolescence and the dealings I do have and the things that spring to mind are of little shits, not the patients, but in the community. And I think of how they behave and I don't, you know its such a difficult age groups that I don't have a lot to do with them on purpose. So when they come into the ward, I mean the ones that we have are nice kids, they're not, they're not horrible or anything like that, but when they do start the sort of manipulative acting out sort of behaviour and that sort of stuff its um, its hard to know what to do with them especially when your talking about. You want to put it back on the parents because they're the ones that have to, you know they're the ones that should have the control over the children. But then you also know the difficult situation they're in and the stress that they're under when their kids in hospital and they've probably got it happening all the time at home. And you don't want to, its sort of that dilemma of sort of how much to actually get them involved in that sort of thing."

D: "But your feeling is that teenagers don't need to be encouraged into using their rights. It's more that they're sort of swayed between the mood thing "

C: "Yeah."

D: "and putting their foot down and completely not"

C: "Yeah, yeah well its just that they I think that they, that nurses are very good at advocating for patients generally and making sure that nothing's happening to people that they don't understand or don't want happening. I mean that varies as well. I don't think that we put in any extra effort for adolescent patients. We just do it generally for patients. We, you know if something is going to happen, we explain what's going to happen and if its something that's going to need written, we still ask "do you want to do this or whatever" and give people the opportunity to say "yes" or" no". Its just the inconsistency between, you know sometimes your dealing with someone who seems really mature and the next minute they're like a two year old and its swinging in between. You can make a really good plan for someone and help by getting them involved in their care, and they think its great. And then the next day it's completely different. 'Well you actually wanted to do this' 'Well I don't want to now. " Its just difficult from that point of view.

social worker

SW" .....And basically I come across quite a number of adolescents just because of the nature of the areas I cover. And I also have a kind of consultancy role (with the other social workers who cover the adult areas that have adolescents on the adult wards as well). So I offer support to them for the adolescent patients that they're dealing with, that they're not that sure about so um.."

D: "Does that happen quite often, finding adolescent patients on adult wards?"

SW: "It depends really, its hard. I can't really put an exact number, but I would probably say a minimum of one to two adolescent patients a week."

D: "That's quite a lot."

SW: "Yeah, yeah, I would like it to be more. But yeah, we get there. Its hard because there is no clear cut-off as to where an adolescent patient will end up. As to whether they will end up in the paediatric wards or go up to the adult wards."

D: "Do you know who makes those decisions?"

SW: "Its kind of um, when they come into e.d. most of them do come via the emergency department. I do not know how they do it down there. I think they just kind of look at the patient and think, oh, they're a big adolescent, they're mature, so we'll send them up to the adult ward. Or they're not so mature, so we'll sent them down to paediatrics wards. So there no, sometimes there's 15 ,16, 17 year olds on the wards. Sometimes they will go up to the adult wards. So its really hard, um, as to why we get them, and why we don't. So yeah."

D: ***"what sort of challenges and problems have you encountered?"***

SW: "Well that's probably the number one problem, is no consistency as to how. I think it would be really helpful to have a clear guideline. OK, every patient, 17 and under, comes to the paediatric units. Every body over 17, 18 and over goes to the adult wards. From my experience of helping the other social workers deal with their adolescent patients they've got, when the adolescent patients do go up to the adult wards, they don't seem to be managed very well because they just don't have the expertise in dealing with adolescent patients. They are very much adult-focused and you have an adolescent that you know doesn't fit into that adult kind of way of working."

D: "So you think that they're actually better on the children's ward?"

SW: "Yeah, I think we have more expertise in the children's ward to deal with them down there. And we're better catered for. There is more resources, you know, they have access to the school and to the play therapy. I think its a lot better that they come down to us. So I think it would be really good if we had, OK this is how it's going to be. 17 and under paediatrics wards, 18 and over adult wards. So I find that quite hard to deal with. I've heard of a few things that have happened to adolescent patients up on the adult wards - like its quite normal for, you know, a 15, 16 year old patient to be in a 4 bedded room with 3, 80 year old adult patients, which I don't think is appropriate. That's quite a common , so I think they should be down in the paediatric wards where they can be managed a lot better."

D: "Do you come across any behavioural problems that you have to?, or is that not your area?"

SW: "um, yeah, we do have a few adolescent patients that come in that have had obviously, like a suicide overdose. We've had a couple of adolescent patients come through with behavioural problems"

[telephone call interruption]

SW: "OK, We were talking about behavioural weren't we. We had a couple through with behavioural problems, um, and that's , we've probably seen an increase in that last month or so. And I, my theory is, because I don't know if you're aware, but our children's and young persons service, South Auckland branches, have no funding until July. They are unable to fund placements for any, unless they are quite acute situations. So what we find now is, they have no funding. They are not funding any placements. So our community services are full up. So that these young people end up here,(which is not an ideal place for them). I don't think we have the facilities to deal with adolescent patients with extreme behavioural . I think that we manage the ones with suicidal tendencies. I think we manage them quite well. But the ones with behavioural problems I think we aren't the right place to hold them. Obviously they have to be special. They have to have a one-on-one nurse. There is the possibility that they may put other patients at risk, and we have such a young population on our paediatric wards, that I don't think its appropriate, um. So we have had a few. We normally manage them here. Its to get them fully assessed, paediatrician site liaison if that's appropriate, social worker imput once they're discharged to go. There is usually a discharge planning or family meeting and then they're referred to our community services to follow up "

D: "so you do a lot of facilitating with the family?"

SW: "oh yeah definitely, definitely. We tend to have a lot of family meetings, especially for the suicide behavioural adolescence."

D: "I know with younger children that quite often the parents would, could come in and stay. What do you find with adolescence?"

SW: "Yeah, with adolescents, not many parents tend to stay with adolescents. The option is there. They are able to stay if they choose to, but I find most of the time, with adolescents, if you have other adolescents on the wards, they don't want Mum and Dad staying. Its like shame, go home stay away. Usually they'll stay for maybe a night, or a couple of nights, depending on how long the young person is in for. If they're in for a week, mum or dad might stay for one or two nights. And its just to make sure that they're comfortable and settled. The rest of the time they leave and come in just during the day. But the option is there for them. Some of them like it, the majority of them don't like mum or dad there. It depends, it depends on the nature of the ward. If we've got a group *of adolescents in they don't want mum or dad there, if there's just one. It depends on the sort of injury, as well how severe they are. Obviously, if you've got a severely unwell adolescent, you know, someone whose had major trauma, their mum and dad will be staying with them, and so yeah."*

D: "So as a social worker what is your main goal?"

SW: "My main aim probably would be to alleviate any unnecessary stress on the family or the inpatient here, just, that's in recognition that they've already , obviously they're a patient here, so they've either experienced some form of trauma, they've had some major upheavals in their life to end up in hospital so if I can alleviate any minor stresses such as whether it be housing, counselling, financial issues ."

D: "So your role is to get them in touch with all the groups that could help them?"

SW: "Yep, or advocating for them on their behalf. Some families are at different levels than others. Some are not able to advocate for themselves. They just want to focus on that young person that's unwell in hospital. So I'm quite willing to take that on board and go away and do those things that need to be sorted out, whether it be housing, or financial, or just getting to the hospital. Or for the out-of-town patients actually having somewhere for mum and dad and the other siblings to stay. For me those are things that families shouldn't need be getting themselves over anxious about. So any thing that I can assist them with, I do."

D: "Who calls you in?"

SW: "Usually most of my referrals are from the staff on my ward, the nursing staff. Occasionally I get some from the different teams. They have like orthopaedic teams ,and plastics teams, um and paediatric team as well. '

D: "Do you feel that, if there is a need, somebody will call on you?"

SW: "Yep definitely. We have ward meetings once a week where we usually discuss any major patients - like anyone who's had extreme trauma, or who's been in for over ten days. We usually discuss any patients that fall into that category, and I automatically pick up and go to see them, um. The other way I get referrals is patients. Families also ask if they can see the social worker for information about the ward. So I know that there is a social worker available. Sometimes they do ask. Some have had experience in hospitals with a social worker, so they do ask. The other way is when I'm down on the wards seeing patients. We have a white board with all the names and ages, and if I can see that there are a few adolescent patients, I usually check through their charts, and have a look at what they're in for. And, if they're going to be in for quite a while, like if they have a major trauma, then I go in and see them. So there's usually not many that slip through."

*D: "**And when you go somewhere to visit, you've got information, you've got pamphlets and information?"***

SW: "Yeah, it depends. Yeah, usually what happens is, I go in and what I do is, what I call my initial assessment, my initial social assessment; what their injury is; how it occurred; who they live with; do they attend school; if they are adolescent patients; um. Just gather that basic information. What support they're requiring. If they've got good family support. Is there any external support that I could be offering them. I'll make my initial assessment, assess what their need is and then pull out *the appropriate resources from there - its all very consensual. I'm not going to go away and do the forms for external agencies without getting the patient informed and without them actually wanting that."*

D: "I guess from my point of view I'm putting together a resource for adolescent patients which will just be a general one. ***Is there anything that you could think of that would be useful to include****"*

SW: "I think just having a list of agencies, of community based agencies - that may be helpful for them. I mean obviously it would depend on what region you are doing, I think that having a list of contact names of organisations (and even having a contact person for each organisation with contact numbers and addresses) would be good. So, if the patient did choose to access something in the future they could. Um yeah!"

D: "Could you write down for me a generic list of the sorts of people that could be useful?"

SW: "Yep I could"

D: "Because that would be something that I could use in my resource"

[break off the tape to look at files]

D: "Are surgical patients covered by ACC?"

SW: "Yeah, surgical patients most of the services that they would require are covered by ACC if they were followed up in the community - things like counselling assistance, transport to appointments and things like that. But medical patients are different in the sense that most of their services would be like - ah disability based services. So I would probably tend to have your generic agencies like WINZ, ACC, and Inland Revenue, and then I would probably be more defined for a specific area. The work of WINZ and Inland Revenue is not so much for the adolescents but for the families' support."

D: "What about the Health and Disability Services?"

SW: "Yeah that's a good service and I think that that would be another good one to have. I mean, you know, we do have adolescents on adult wards, but I don't think I have ever had one who actually grumbled about being up there. They probably have no idea that it's - yeah - that it's their right to grumble and moan and say: "No, I don't want to be here, I want to be down there!"

D: "And quite often I think patients are quite overwhelmed as well!"

SW: "oh yeah!"

D: "So they can't look at it objectively?"

SW: "Yeah they're not fully aware of what their rights are, so that would be another good one to write down."

D: "So if I wanted to get the best organisations to go to from an area, I could just go to a social worker and they would be able to tell me which ones it would be most appropriate?"

SW: "Yeah, definitely! Like I have a list - this is my resource file here. [She points to large grey filing cabinet.] It's pretty big but its a blessing because I use it so much. I have to have quite a wide range of resources there - um - but I think I mean there are certain agencies in the community that I tend to favour over others, because I've used them more often than others and because I feel quite *confident about the sort of service that I will get from them. So I have my agencies that I use, whereas another social worker that covered a different area would probably use different resources. This probably would be different from region to region - yeah - but I think that those would be the main ones that I would tend to use definitely. I mean that if you were going to be doing a resource, you should be using internal references like your social worker, chaplaincy, and cultural supports. These would be your inpatient services and then you'd have your external services and your community resources. I think that that would be a good starting point to definitely have in, and maybe even having a page as what your rights are as a patient."*

D: "Yeah I was wondering about that"

SW: "I mean that's great - um - that one right there"

D: "I see you've got a poster on your door about children's rights."

SW: "Yeah, that was um that's just - um - that was done before I started here anyway, and its always been around. I think that's really great, I don't think I've seen it anywhere else. So - um, yeah - even something like that, to have a page on "OK, what your rights are as a patient". I think that would be terrific! It could be like, you know, those little cards that the police put out. I don't know if it is the police no its the youth health project that puts them out on "Know your rights when your arrested". Have "Your rights in hospital" instead. That would be terrific to have something like that, because half of them donate. I mean: one, they're overwhelmed by their injury; two, they're anxious about being in hospital; three, it depends on what their family supports like. If they have good family support or if they don't it really makes a difference. It's the last thing that they're going to worry about. It's just like "Well, I'm here, and that's the way it is really." But I think it would really help their recovery rate if they were somewhere that they were more comfortable in and had resources there for them."

D: "Is there anything else that you would like to tell me?"

SW: "No not really. We've had a lot of discussions recently just within paediatrics. We actually have a group of us that meet quite regularly and discuss adolescent issues."

D: "You sound really focused about it."

SW: "Yeah, we would so much like to have an adolescent unit. Maybe not a ward as such, but maybe half a ward, maybe 11 or 12 beds for adolescent patients to be in so they're together and they have a space of their own. At the moment they're neither here nor there, you know. We think its really important so were really trying to push that!"

SW: "I mean and for us, if we can reduce the rate of adolescence taking of from the hospital (because I mean we do have quite a few adolescence that just scarper). You could understand why! I mean, if I was in a four-bedded room with three 80-year-old males that were in like terminal care, I would probably be freaked out if I had never been in hospital before. If I had never been exposed to that, I would freak out too, and go. So you know so if we could stop things happening like that, it would be nice. So we're trying, I think. We'll make some head way, we've got the support there, so - yeah - that would be great!"

2 nurses - adults' ward

Audiotape: ***No*** *Comments:* ***young nurses who were not focused on interview in open busy reception***

Number of patients on average in ward: one every 2-3 weeks

Length of stay: half a week on average, sometimes have 2 or 3 at a time

Problems or challenges: *they are in with older patients so they can be quite isolated.*

Some like being with older patients though.

Their communication is not good and they tend to be very quiet.

They are sometimes very embarrassed when having to face their own body fluids and intimate questions.

They are very particular about having the curtains pulled around their beds.

Less communicative generally with people that they don't know.

Not able to give them separate rooms or mix the sexes on the ward

Concepts or Ideas: *Placement with other young people.*

Activities and games: *TV room where they can sit with their friends when they come in.*

Books, magazines TV

Suggestions: *Not much can do.*

charge nurse-adults' ward

D: "How many patients on average would you have on the ward?"

C: "teenagers or patients?"

D: "teenagers"

C: "A year, probably 12-20 maybe. Um because we're not only a cancer ward, we also have haemophiliacs as well. But you're wanting information regarding cancer?"

D: "no its just any teenage patient"

C: "then there's the Haemophiliac group. Have you been given any information about that?"

D: "no"

C: "they may be able to help you because we have. I know that they're older than 20 now. They've gone through the teens. But there might be some coming up."

*D: "**can you describe the problems or challenges that you have encountered in dealing with adolescent?,***

C: "ah ha, they're certainly a challenge "

[interruption phone call]

C: "they certainly more challenges. And I would call them more challenges than problems. Challenges in that they, um, their age, and what they're doing. And, I think, as you get older as a nurse, you can loose touch with what is being a teenager today in the nineties, So, um the challenges are often if they're young, they are quite young when they are diagnosed. If they're diagnosed at 14 or 15 they often come straight to the adult ward so they don't actually go to the children's ward. If they're diagnosed maybe 12 13 they may go to the children's ward and come onto us at some point in time. So you know, a young 14 or 15 year old teenager on an adult ward is usually pretty mind *blowing really. They find it quite difficult in that they often. I suppose you could get many types, but some of them want to be in control of the information that's given to them and everything, and they want to lead, I suppose, lead with their parents or be equals, in a sense, in their intending to be a kind of adult. And often feeling your way for nurses. And I think that that would apply for medical staff. Where do you call in or when do parents have to be present. I mean obviously when consent is being granted for procedures and that. Like we do need parents if they are under the age of 16. I think 16 is the age but then you have patients you know, teenagers that are 17, and you think, really you know those parents. Do those parents need to be there. And trying to encourage the teenager to say, hey look, why don't you get your Mum and Dad in here because you know, I mean, this has got some pretty big implications on your life. And you know what is afterwards, so often its that very tricky thing of trying to gauge their maturity or their understanding of what is going to happen for them. And its like that for any patient, and I don't think that's any different for a forty year old or a 16 year old, where do you get? I suppose its really important in the initial time that you meet them, is that you try to find out where their support is. Are they pretty reliant still on mum and dad, are they still living at home, um, or have they moved on from home. And, um, what do they use to get through? You know, get through their everyday life ,let alone get through their life now with an illness. So things change, um. So those challenges are not exclusively, not always exclusively teenagers, but, um, often just their age. And trying to ensure they have a good understanding is really importan,t especially in regard to, you know, a cancer diagnosis."*

D: "You've got people who can come in, like you would bring in groups like CANTEEN"

C: "Yeah, and often we would. Say if you have a newly diagnosed patient with say, leukemia, and the teenager is, you know, dealing with it pretty well, we would often offer to them 'would you like us to contact CANTEEN?" and tell them what CANTEEN is and see if they would like to meet somebody whose gone through it and to come and talk to them. And that is often really helpful um"

D: "So most people would choose to?"

C: "Yeah, most people would choose to do it, because its like , and I've found that from what I did, people understand knowledge from people who've gone through it better. It would be like us having to have a dmc. You'd probably, if you had a friend that had had it, you'd ring them, though you'd take the official knowledge from the doctor, or whatever else you'd actually want. Somebody who'd actually done it to actually give you the story of what it was really like. Because its not, we haven't, I mean, we haven't been through it in a sense. We may have cared for a lot of people having it, but we don't know what its like so we can give them the value of our experience. But we haven't lived it. So were really a bit out, a bit out to the side. But often we'd get, we'd definitely get teenagers in and try and level them up with age. And ,um, you know, they're welcome to come into the ward and be with them, um, and talk with them really, um. Problems, I guess I wouldn't really call them problems. I'd call them more a challenge, um, in the sense that anyone that you diagnose is a challenge. So I don't, I don't dread, oh heavens we've got a 15 year old with leukemia coming onto the ward, oowwhhh all that noise and all that. All those hormones going through, no, no its more."

D: "you don't experience them as reacting differently or as "

C: "No no um [pause] no I think that you have the whole gamut of reactions. And, I mean, you get *that often at any age group. And I don't see that. No, they don't start flying things around the ward and making life hard for us, um. Dealing with adolescents they are a challenge. Yes. We had a young boy who, um, would have just been no, he was actually a bit younger and we were treating him [hesitation] yeah. Its often supporting their mum and dad, but making sure you don't give more information to the mum and dad. So you need to try and, um, because mum and dad, in their role, in being their family, often want more information or a different probably they would be there when the treatment plan, or whatever, was going to be discussed with the teenager, and they would be there. But often they would be seeking more and on an adult level, saying ok you've told it to Joey there, can you really give us the you-know-the-bit, and you know, if they're over the age of 16 ,really you can't give them any. I mean you have to repeat what you've given them and hopeful, in the sense that you should have given Joey the full picture too. And it's the whole thing when you're communicating, when your communicating with them. And its like that with any patient. There's been studies that they only hear about 30 per cent of what's said. So you're dealing with so they heard the diagnosis and then for the next ten minutes they don't hear anything and then they pick up bits. So its really important that their family or friends, or mainly important that their support people, are around to hear the story. I mean, I often nursed teenagers where they get a bit resentful if they think mum or dad knows more than they do. So you have to ensure that you know that that's not so. And you know when things are not going very well, and they're fairly miserable, they often ,you know, act like a ten year old. And then when things are going really well they're fairly grown up about it all. So its just like anyone really, its how they get through it.*

D: ***Can you describe any information concepts or ideas that you have found useful in helping patients?***

C: Probably getting someone in of their own age and getting them to talk about their experience is the most, is one of the best ways of doing it. We, um, in the study I did, was about information and how it moved,and the amazing things that goes on in the ward amongst patients,um, and how you know. They compare how they're doing with each other and they talk to each other about this and they you know. I had that the other day and this is what happened so we actually "

D: "Is that information or misinformation?"

C: "Well hopefully its good information because if you actually give them good information it will carry on to be good information. Often if the patient's experience is horrendous, well then it might become misinformatio.n"

D: "do you have ah..."

C: "but we have no control over that and that's in that sense that we're seen as official as such. Where as the information swapping on the ward is just, is unbelievable, its amazing how much goes on".

C: "yeah, ***any information concepts or*** *...I think that the important thing is, you know, I mean, is being and treating them as an individual. And just coming to them when they are frustrated or when they're angry or things like that. And just, you know, just being with them and trying to get what they want. And trying to achieve what they want and sort of ,and yeah support, and often I think with CANTEEN they often run a cycle when they're in treatment and up to about 2 or 3 years* *later. They are quite happy to be involved in CANTEEN and then they're, I mean, if they are in remission or cured as such of their cancer, then often they drift away from it. So they need it when they are unwell or going through their treatment. And then, once they actually get their life back and get back to their study, then their own support systems outside just pick up again".*

D: "It would make quite a nice transition I would imagine compared to some of the other wards, ah, back into society."

C: "Yeah, yeah, "

D: "Having a group like that?"

C: "Yeah, yeah back to school Um, ah, yeah, back to study, back to university for some of them, um, and its as though they have a sick life and a well life. Often, when they're sick, you really have no concept of their life outside. If they're on the ward or something like that. So, when these, you know, I mean often initially, often they have a lot of visitors of their colleagues and friends and that. After they have been in a while, its really only their good friends that actually keep it up. I think, well children, well teenagers probably, find illness quite hard to deal with, and sort out. Really the whole thing is not supposed to happen to them, um and that. And often you find that for the first couple of weeks you get a hell of a lot of people visiting and then it gradually peters off and reverts back to mum and dad and just a couple of good friends really."

D: "Is that all right on the ward having all those people coming through"

C: "Yeah [cough] we don't have any problem with it. We don't, I mean our big problem is space really. So, I mean, more than 4 or 5 round a bed is often a bit too much. So we often say, look why don't you go out for a coke and come back and swap over. And if they're in a single room, you know ,7 or 8 in there doesn't worry us, you know, so long as they're not in isolation or anything like that. But normally at those times, we restrict visiting a little bit. No often the more the merrier. We don't have any limited times. We have open visiting. So often they'll just wander in, usually about 9 o'clock we ask people to start going but some patients get a bit tired [laughter] of people being around.

*D: **Are you aware of any publications resources or activities?***

C: Um I know there have been some. There is some work being done by the cancer society for adolescence, And they were actually looking at trying to develop something up there. But, as I say, the numbers aren't big. But when they need it they need really quite intense support. But I mean how much of a programme can you run for 10 to 15 people a year? Um that's usually the criteria for most things, you know, money. And how many there are really, um, they go away on camps with CANTEEN and quite a few of the staff are involved. I mean, Johanna used to do CANTEEN. Quite a few of the staff have been involved in going away on camps and giving up . Well we usually give them a weeks leave from the ward to go to camp with the teenagers as such um so..."

D: "what about the sort of activities, I mean is there a TV room for a TV and that sort of thing?"

C: "we have quite a few TVs, I think 10 or 12 on the ward. So often we just get a , we have a play station for people who want to play computer games and that sort of thing."

D: "and a VCR?"

C: "and we've got a VCR. So, and often parents will arrange for sky to come in and that sort of *thing. but most beds have a TV and usually set themselves up, um, music wise as long as they've got headphones on they can play it as loud as they like [laughter] ah."*

*D: "**so you actually do have some resources, activities and games"***

C: "Yeah. its more. Yeah. filling in the gaps really. Its the spending in time which I think they find quite difficult. I suppose, if they get really, they get really bored with being in hospital and they just want to remove themselves from it."

[interruption of telephone]

C: "Yeah, so there are a few activities ,um ,and often if CANTEEN meetings are on, they often go across. They often go across there or have them over here in our centre, down in outpatients, where they go to meetings. We have a fairly good process, with patients ,especially, with the haemophiliacs or the haematology patients, where we get them out on leave as much as they can."

D: "are they here for quite a long period of time?"

C: "if they are a newly diagnosed leukemia they are quite intense. Its sort of for the first 10 weeks its quite chemotherapy, getting them through the chemotherapy and then through another course."

D: "that's as an inpatient?"

C: " as an inpatient, but during that inpatient time we try to get all their drugs organised for two times in the day, and get them out in between. But mum and dad are often working. And, you know, I mean its probably a climate for getting out. and you know their friends at school or whatever. So they're often quite alone. So, you know, those kinds of activities playing on the playstations or "

D: "would you have more than one young person on the ward at the same time?"

C: "not necessarily. No, we seem to, you seem to have them in fluxes. You have, you have none for ages, and then you might have one or two. And they usually meet up, you know, depending on how they get on or whatever. Whether they catch up with each other and a lot of the, and often the older patients, you know, cancer patients. Cancer is a disease of the elderly as such over 60 is more prevalent. But we have a younger people in. We have a whole population that have it. But often its interesting how the older, you know the people in their 60s, give them a bit of attention, and yeah, and chat to them, just as they would a grandchild or something like that, and yeah, and yeah, they often come back in and ask how so and so is. But normally we try and get most of their treatment as a day patient and get them home as much as we can It just avoids, you know, hassle and they more normality for them, yeah and that's about it. ah

*D: **could you suggest what would be helpful to include***

C: probably having, you know. If you're looking at a resource for adolescents, how they make contact with people like CANTEEN, people having information there for them, and telling them about what they do (although we usually know what CANTEEN do and get up to and stuff like that) um I don't know about publications or books with teenagers, if there are a lot or whatever ahhhmm yeah. I suppose the way you'd present it as a resource. If you'd use different types of media, whether you'd use a video or something than that would click better than a written piece of paper probably. Would something on the tele, you know. If you put the resource on video people would *maybe find that helpful, rather than having three sheets of paper saying that what was available in this region Ahhh, no, I can't think of any other suggestions really off the top of my head no."*

D: "ok"

C: "no, no that's about it But I would imagine a video or something like that would be more applicable or more used or whatever than having the written. A lot of our information does get written and there's lots of things like 'how do you inform people', 'how do you inform people', ' what is the best type of presentation', you know there's all these studies done about how to communicate with people. And, I mean, that's what your trying to do isn't it? Is to communicate information to people so that they can be probably, yeah, probably, video. I think that's about it.

D: Is there any questions that you want, like to ask?

C: I suppose my main focus is cancer because that's where we work. Cancer, haematology or leukemia's. So their in for a fairly challenging time for the next, well, I mean, for the next often their treatment is fairly solid for about 18 months. And then there is always that potential that they don't go into remission or whatever."

D: "you know you.re dealing with a lot of psychological issues as well. Like life span and future and all that sort of thing"

C: "Yeah, fertility, um ,ah yeah. Will I reach my potential in terms of height if we're giving them a lot of radiation or chemotherapy, um"

D: "Do you have anything that's written or any information that helps them through some of those processes?"

C: "We're not that brilliant on written information. We give a lot of verbal, but were not . There's certainly not that much written at the moment. There is a lot of potential because the because these teenagers haven't reached their potential as such for growth so and a lot of the agents that we give can actually stop their growth and certainly their fertility."

D: "does it delay it or does it ?"

C: "It can delay it and or it can stop it, depending on the amount of treatment they're having. With fertility, and the ability to have children later in life, certainly. And that's often what, you know, I mean a 13 or 14 year old might not even be thinking about that. Mum and dad might be very worried about that and,you know, seeing "

D: "how much you give them?"

C: "yeah ,how much to give them and what is the right stuff to give them. In a sense, I mean at 14 or 15 for males, I mean, we can offer them a sperm bank and it to be frozen. Where for women that facility of saving, of you know, doing eggs, saving eggs, is not available at the moment. So, um and its often, its those issues that mum and dad are more worried about than the child actually. So there I suppose, its that expectation that they will reach adult hood. Whereas often, um, they've got this big stumbling block to get over before they get there."

D: "I've been looking at teenage patients on adult wards as well. So a lot of them are there are no resources or people there who are specialised in helping them through . Whereas I think with cancer, there is a lot more resources which help. Just in the knowledge that the people have. "

C: "Yeah and I think yeah often when it comes….. I mean, often when nurses on the cancer ward come to cancer ward because they want to work on one, so they're often a bit different to or we like to think that they're the best. "

D: "very special?"

C: " Yeah, and working on a cancer ward you're actually opening yourself up for some fairly heavy duty stuff. I mean you have to think, probably about your own mortality. You have to think, what if I got this? um and you, I mean for the first year you often live in dread as to 'is this patient going to ask me if I am going to live or die you know and you feel "

D: "and does that actually happen much?"

C: "It can happen, yeah. I mean some patients It depends. I mean, if you develop a really good relationship with a patient they will actually challenge you with those questions."

D: "Do you feel as if you are well enough trained to deal with that sort of thing?"

C: "I think you learn the skills, um. That doesn't mean you get it right every time. I think, you know, ahh, I still have moments when I do a bit of clinical time up on the ward and I come out of a room and I'd think, I've really mucked that one up. And I have to go back in there and say, look, lets start again. You just go off on two different tangents and the patients doesn't understand where you are and you can't understand where they are either. So you have to go back in. But communicating with patients is really the biggest part of the job, whether its written, whether its educating them whether its talking about what's really important for them - what they want to achieve. And I think nurses, on the whole, have a different focus in the sense that we have more a, 'what is it like for that patient, and how can I support that patient to get through whatever they have to get through'. Whereas medicine is 'this patient has this disease. This is the treatment. Lets fix it. We are What's it like for them. Lets walk with the patient in a sense and support them as they go."

D: "what has come out of talking with people is (that) what I could do is come up with something that helps the patients to ask the questions"

C: "yeah"

D: "or to facilitate them in telling them some of the information that they could gather from around them."

C: "Yeah. Yep, and often they don't know who's important when they come onto a ward. And learning to know who to seek assistance from is really important. I would say that communication would be 80% of our job. Getting it right most of the time. There is a lot of other tasks that we do. But if you can actually communicate well with your patient, I mean your battles are nearly over. You know, I mean, with your patient and their family, you can't separate either, but you then have to be aware. Like I mentioned before, what information do you give? Do you share it and ,um, that all has issues around privacy act and, um, in a sense, if a patients relative rings us or you know a mum rings us and asks about her Joey, um, you really need to give the phone to Joey to tell her. I mean we can't - the privacy act has, I think, stifled the amount of information that can be shared."

D: "Is that, is that with the changes that have just happened? I mean, has it got harder?"

C: "It has got harder, um, and ,um, you have to be sure that the patient has given you consent to give out their information. And then they have to say, well, what is the limit of that information that you can give people. So that really has got quite a few connotations and for teenagers. "

D: "what do you say if someone rings up the hospital?"

C: "well their condition is fair or whatever. Whatever the nurse has designated their condition as. And if you'd like to, you know, if you want to know more, well hand you over to the patient. So its the patient who does the talking and not the nurse. And it makes a lot of families very frustrated because they want the inside information. They want to know, yes. And the outcome of that is a lot more meetings with families. And major family meetings where the whole, where, you know, we ask the patient, 'look we think it would be a very good idea to bring everybody in, um, and I think that we need to talk about these issues'. And 'you tell me what you think, if you're happy with that, then, we'll arrange it."

D: "I notice that you have the health and disability act on your wall. Is that something that, um ,you think . I mean, how do patients become aware of that, and is it something that they should be aware of, and are they aware of it?"

C: "um not necessarily, no. (In) the health and disability act there are 6 or 7 points that its talking about, you know, informed consent, getting consent. I mean the relationship with health professionals and all of that. I don't think the patients really have a working understanding of that."

D: "would it be useful if they did know more about it?"

C: "Yes, in a sense, that if you were looking at a resource, that these were the things that were your rights as regard to being there. And ,um, and I think there is a pamphlet regarding the privacy act too, regarding releasing information about you, um. But a lot of, I think, once initially when they don't know the system, they get very frustrated with us that we can't give them the information because the patient hasn't told us that we can um. Once they learn the system, they know that the patients are pretty informed. Probably more informed than anyone else. And us handing them to the patient is the information that they want to know anyway. And they can translate it. But some patients don't want their families to know things. (They) want to withhold stuff. It becomes difficult. But we try to obey what they want. When they are the key person, really they become more important. I think, with the privacy and the disability thing, rather than the family. I think before, it was a reasonably equal balance, but know the patient is really the focus and "

D: "so that's a good outcome?"

C: "yeah, it is, it is as long as its a nice healthy family unit and there's no "

D: "hidden agendas?"

C: "well its amazing. The family histories that come out of the woodwork too. I mean, you just think. I mean you start off and everyone looks really normal you know. They come in for a family meeting and everything's going all right and then a month down the track there's people falling out with people and its just....."

social worker

They liaise with CYPS and Police. They co-ordinate between Nurses, Doctors, CYPS, and Police.

There is an initial assessment to work out what can be done. Whether there should be a court order or that child should be placed in extended family.

The aim is to make sure that that person is safe. They get many referrals from younger kids but they peter out by the age of 14 although the service does cover those up until the age of 17.

Whether that is because the young person is not aware of the service or because they are not bold enough to ask or it's not cool to ask for help, we don't know.

Perhaps people think that they are adult enough to deal with their own problems, who knows?

Note: CYPS Act 1989 has the philosophy in it"

We ask questions like: "Do you feel safe at home?"

Can you tell us if there is anything done to you that you feel uncomfortable with or that you don't like?

An example is a 15 year old male beaten by his father but he says that it's all right because his father was drunk so he wouldn't ask for help.

Or a 15 year old female comes in for the morning after pill with a 25 year old boyfriend. Is this abuse?

Places of Help: Family Planning, Adolescent Clinic (which provide free confidential Sexual health information).

The focus is on protection and support and informed choices of young people.

It would be useful to have space for a blurb

There is a big need in this area but it is difficult to get access to these young people.

A proportion of those hospitalised are for abuse, not just physical but emotional and mental also.

charge nurse-adults' ward

N: "We haven't actually had teenagers for quite a long time"

D: "for a year?"

N: "ah, probably yeah"

D: "that's not just for cancer, but for haematology?"

N: "for haematology, which is sort of like leukemia's or blood disorders. And they may, some of them, go on to have a transplant. So we've had a few in years gone by, but just recently we haven't had many at all really."

D: "are they repeat, are they quite often repeat admissions?"

N: "Yes, yeah, say if someone gets leukemia then they're back and forth antibiotics and that sort of thing, and then they can come back for the bone marrow. So yeah, they can be in here for quite a long time"

D: "so you get to know, so its more like one or two people , but you would get quite a close relationship"

N: "yeah, Mmmm with most of the patients, because they are back and forth all the time, you do get *to know them quite well. But, um, I'm just thinking of the last boy we had. He would have been 16 or so, who was in here for a bone marrow transplant. And when he was in here, he was quite difficult to communicate with because he just didn't want to have much to do. He probably just wanted to get on with what he was doing, yeah. There was no chitchat [laugh]. So that is quite hard really, when they are like that."*

D: "what sort of things did he do?"

N: "um, you see he was very good at art, and he used to draw a lot. When he was well enough to. That was one of the main things he did really, and watch TV. One of the things that they, well younger patients and, generally patients in their twenties will as well… they've got Gameboys and Playstations and that's very popular."

D: "and you've got TVs?"

N: "Yep, TVs and videos. And , they donated a TV to the ward -specifically for you know, teenagers. I mean, it just is in the general pool of TVs that we've got. But that is one of the things we've got that we can just put in front of a teenager and its sort of first in best dressed. But it really hasn't been an issue, um, yeah. And they use those in the hand computer games"

D: "Yep"

N: "it depends too on how well they are. Because sometimes people are just too unwell to do anything really. That would be the main things they would really do. Yeah, videos and were getting a bit ahead of ourselves here I think"

D: "that's fine"

N: "rambling on [laughter] um, have you had anything to do with CANTEEN for teenagers with cancer?"

D: "I contacted them earlier and they said that, because of the privacy act, they couldn't give me the names of any people, but I thought I might go back and talk to them having got this far"

N: "Yep, yeah you see that's the thing, yeah well it varied. Some patients we had on the ward (you know it wasn't their thing at all). Sometimes, I mean CANTEEN changes too depending on the membership - depending on what they're doing. But the main thing they seem to be going into is going to Macdonald's and things like that. And a couple of the guys that we have here, I mean they were of that age but they just weren't into that, I mean one guy was doing Classics at University and that. And I mean, he wasn't at all interested in that. And another one who, yeah, he didn't want to do things like that. And they were sort of older than that. But they would be an exception rather than the norm those two. 'Cause we've also had people who are older than the CANTEEN age group who have gone back and have still been involved with CANTEEN so…"

D: "so how many people would be involved in CANTEEN?"

N: "well it varied. Because CANTEEN involves brothers and sisters as well as the patients. That's the whole thing is that you know, often, if a person, if the child gets cancer, then they get all the attention and the other kids get left to their own devices. And that's one of the things with CANTEEN that they be involved as well. So its very much a support for them. But sometimes we would have about 20 because we'd have monthly meetings both in and out and whatever and you'd get a dozen or so people involved in that".

D: "so the idea of CANTEEN is that they have the opportunity to go out and do things together?"

N: "Yeah, and the support thing. They also do, um, grief workshops and other counselling. Ah not so much counselling, but every year they have a national camp. Its a nationwide arrangement and they like, every year or two , just so to know they can feel at ease with each other, you know. So they don't care if they have bald heads or all the problems that they have"

D: "so they would have a collection of resources and materials. I mean they would have information like books being written about teenagers and "

N: "We've got a video too. I was just thinking that might be of use to you I don't know."

D: "a video of what?"

N: "oh from CANTEEN. Its just something about CANTEEN so that could be some use."

D: "yeah, yes."

N: "and they come and visit people on the wards too, as a support sort of thing. And often, once they have gone to these camps, they have made friends all around the country side. They, you know, write to each other and call on each other. So it is quite a useful organisation. And the same thing, like that some people get a lot of benefit. Like that with people coming into visit them. I was just thinking of a young girl we had on the ward, she had a bone marrow transplant and she came from Hamilton. And so, having the CANTEEN people down here was quite good. But then that's, yeah, its while she's all right. Because then, when they get sick too, the CANTEENers are wanting to visit them too. But you know, they're not really up to it. ***Number 3,*** *that's the only thing that I can think of. You know, CANTEEN and that. You know, but the Haemophilia Society, I'm not sure about that - if they have anything. I know that we had one boy who was in CANTEEN who was a haemophiliac and he had a few things too. But haemophiliacs would tend to come in when they are a wee bit older. "*

D: "also the information that you give to patients generally when they come into the wards like, I've found in other areas in the hospital that the wards have put together their own packages of information that contains like the wards routines."

N: "yeah, we don't have a specific thing like that. Its usually more if people are having chemotherapy. You give them handouts about that sort of thing, yeah. Um, one of the nurses whose doing and ed, she's an educator but its part time. Other wards have a full time educator. She gets sort of two days a fortnight to do that sort of thing. So every thing happens pretty slowly. she's doing a package for people doing bone marrow transplants. But it wouldn't there's nothing specifically targeted to adolescents. A lot of the information we give is verbal. But we've got specific handouts for people who've got, you know, chemotherapy, things and mouthwash. Whereas others, you know, sort of, they are all separate. The ideal is that eveyone has their own little package things. Something, but that's a long way off.

D: "so is that something that you're looking at developing?"

N: "Yeah, but its um "

D: "or you are just developing because the packets are there?"

N: "partly that. But part of it . Its more the haematology patients that I was thinking of. And *more, as much as treatment, as much as anything else, like where they are in their treatment plan, and that sort of thing. Its more treatment than just general information. There is a cancer pack thing that people get though, have you seen that?"*

D: "No, I would be interested to see that"

N: "Oh I can do that."

[discussion about giving out questionnaires]

D: "is there any thing that you can think of that would be useful to give to patients while they are in hospital? "

N: "Not off hand, but then I'm not very good at that sort of thing" [laughter] "not because there isn't anything"

D: "well what I've got out of the interviews so far is, that basically, if I could give patients something that helps them to ask questions, that sort of facilitates them to ask questions of people "

N: "yeah, cause communication is often the big problem I guess. But then that's a, I mean there have been other teenagers who have been fine, you know. They're just delightful. Its just this last guy I have been thinking of who was, yes, he just wanted it to be over and done with. He didn't want to dwell too much on everything so that . However, there's no two ways with him going on."

doctor-special interest teens

*S: "Now this **challenges with adolescent patients** is this all up with everything that you do?"*

D: "Yep, yes ah, just anything off the top of your head is what I've been going for. And as people go down the questions they just find their own way into something."

S: "Right, right...Well adolescent health is a new developing field in New Zealand. There's not much really. The rest of us sort of find our way among ourselves and do a bit of reading. That's the thing, and go to a few conferences. Yeah... so.... "

D: "So the adolescent role you have got here is in addition to your other work that you do "

S: "And I believe that needs to be an in patient unit with a liaison service. Because obviously you've got to reach out to adolescents in more complex parts of the hospital like intensive care, the emergency department "

D: "You're looking at getting, you're hoping to get some staff that are just purely for adolescents "

S: "Yes, I think ideally we are looking at a unit"

D: "But that's not part of the children's hospital"

S: "No, and I don't really think an adolescent unit should be in a children's hospital. I think it should be close to the adults because that's where we want to move"

D: "the transition"

S: "Yeah, when children go to an adolescent service they're developmentally moving away from the child view of things to the adult view of things. So I think that to move them to the adult side of things is the way to go. I think it should be in the adult part of the hospital "

*D: "Maybe we could start looking at the sort of **problems**... it doesn't have to be with adolescent* *patients themselves, it could be in getting staff to deal with them."*

S: "I guess, if we look at medical staff, which is the one I know most about, the difficulties we have with medical staff in dealing with adolescents is we're very organ based or disease based in our approach. And that's often how we're funded. And that's the way we're trained. And I think adolescent issues don't often fit comfortably into that. So you get plastic surgeons who are very comfortable in dealing with their operations and their burns, and, but, if they have to deal with other things like a young person who may have a substance abuse problem, or hasn't been in school for two years, then their not interested in that because it takes up time, and it takes up money, and they don't want to deal with that anyway. So you get a lot of doctors in the hospital setting who don't want to deal with adolescent stuff. They just want to do their bits. And so there's a bit of unwillingness, I guess, in to recognise adolescents as being a special group that have got big needs. And in hospital we have more than 4000 patients a year in the adolescent age group. A big, big, group. A lot of them are obstetric, gynaecology, trauma patients- which are the biggees in adolescent health. They're a group that, if we could have some input while their here, we could have a huge health gain in our community. If you could pick up a teenage mother, hear and spend time with her about child health, community support, so if you could do that here before they get chucked out, it would have a huge impact. A positive impact for the mother and the child "

D: "So it's a real opportunity.."

S: "It is"

D: "..to solve some of the problems "

S: "it's a huge opportunity. And we know from the literature that young people who come to hospital there's always educational problems, substance abuse, suicide . And ideally every young person who hits the doors at Middlemore should have a needs assessment which could be done by a nurse or anybody it doesn't take long."

D: "So that their needs can be targeted directly?"

S: "yeah, and you don't have to necessarily fix everything here. But you could when they leave, put them in touch, or get someone from the community to come in and pick them up while there here, if you found, you know. The classic is the young person who comes in with a fracture, or they come in with pneumonia, and you find out that they haven't been in school for two years and they're abusing various substances, and socially things are not too good. I mean that's the classic case that comes up again and again and, um, I guess we . Because, in the hospital our focus is on the disease, getting them out of hospital as quick as you can to save money. We don't sort of pick up on, we don't want (to) ask the questions basically, because then we have to do something [laughter] so um yes. So, to shift around and have an adolescent focus is quite threatening to um "

D: "a lot of people"

S: "the hospital staff. "

D:" to the hospital system as well, because the whole thing is just not geared "

S: "So, it's quite a challenge really. But it's a very important one. We know adolescents are the , well they're really the only group that is not making health gains. If you look back over the last decade, everybody else, their morbidity and mortality is improving, but with adolescents it's not, it's getting worse. "

D:" There's not...Well I guess I should be asking you ***what sort of resources are there for adolescent patients?***"

S: "In the hospital now?"

D: "Yes"

S: "There's not much really. We've got some play therapy time. We've got teachers and that's about it really. "

D: "So do you know anything about the adolescents on adult wards? Are you aware of them at all?"

S: "We don't really hear about them. The only time that I get to hear about them in hospital is if we're asked to have some input, and that doesn't happen very often. For example, they might have a kid up on an adult ward with rheumatic fever and they don't have the guidelines for dealing with rheumatic fever so, sometimes, they ask the paediatricians to help. Or, I've been asked occasionally to see young people with developmental IHC educational needs. And the adult physicians don't know how to deal with the adolescent stuff. In the community, in our adolescent specialist clinics we sometimes find those patients. They sometimes get referred to us as outpatients "

D: "As outpatients? "

S: "Yeah, But we haven't actually set up the inpatient service yet. So we don't really get hold of them here in the hospital, out in the field we do. But then that would not be that many,'

D: "Part of what I thought I could do was to help to facilitate the patient to ask the questions-especially for some of the patients on adult wards who don't have the services and supports that you have in place for the younger patients. Initially I was thinking of getting them in touch with the resources inside the hospital itself, but since I've been talking to the social workers I've been realising that there is also probably a place for putting in information, getting in touch with the information, as you say, as an outpatient, but that happens anyway?"

S: "It only happens if one of the physicians thinks about it, and they probably don't know that much about the service anyway. Probably what we need to do is raise our profile. And we will be doing that. We're going to have a combined grand round with the physicians in June and then we'll hopefully . I guess, to start with, I'd like them to have a couple of names and phone numbers to ring. You know ,as a start. "

D: "Because there's all these. It seems to me there are all these really, really, good resources that maybe some people are not getting access to "

S: "I guess it is really part of our role to go out and tell people about ourselves. We haven't done that yet "

D: "I guess, ***have you any ideas as to what to put in a resource that would be helpful to patients***"

S: "I guess the main thing is . It's difficult because, at the moment, we haven't got enough. We haven't got much to offer them. But, I guess, if you can at least let them know what is available, that's a start. I think it would be also nice for young people to have some information on their rights and issues of consent, privacy and that sort of stuff. I would think mostly people aren't that well informed about their privacy and their rights to health, and the health information that they *have their parents something along those lines would be useful."*

D: "Yesterday, I got this information designed for teenagers overseas."

S: "Right."

D: "I am actually thinking of something a lot more visual. Because, being a design student, I want to make it a lot more interesting. But would some of the same information to that, something like that be useful?"

S: "Yep, that's really useful too. When you talk to young people, when they're frightened about the whole experience, its very disempowering who the people are. Having a sense of what's going on and who everyone is, and where they fit in the hospital is, would be, very useful. Certainly the young people that I talk to with chronic or life threatening illnesses, the kinds of issues around fear and loss that's probably a whole other book. You need to write [laughter], you know loss of body image and previous things they could do and fears for the future."

D: "identity."

S: "That kind of book would be very useful, I think. I'll show you this I haven't looked at it much but I like the "

[break where designer describes what she intends to do with the project and its outcomes]

S: "When you're thinking about information to offer young people there is sort of services that are evolving at the moment. "

D: "I think what I could do is (to) have a series of bites of information and each one could be on a slightly different topic - like community support, or pain, inside the hospital or whatever. And within that, I could have a little bit of information, and a little bit about how to get information. And as I design it, I can keep it quite flexible so, if anything like that comes up, I can slot it in somewhere so it can be tailor made a little bit. Because the information will have to be different for Auckland and Wellington and that kind of thing.

S: "Right, I see what you mean"

D: "So long as I get the generic sort of thing working"

*S: "**Information, concepts or ideas**.... I guess from my point of view when I see young patients that present with whether its a medical condition or an injury or if its an assault or whatever, I think a couple of the pivotal things that I say to young people are one is getting the information to them and the other is treating them with a bit of respect which is often something which they haven't often experienced certainly there is a huge difference in the way that we treat adolescent patients "*

D: "You mean they're treated more like adults?"

S: "Yeah um not quite like adults, a slightly different focus I guess. But yea much more so. We spend maybe an hour and a half with a young person. and its very much along the lines of were here for you and this is your issue and we talk about it and what do you want us... this is what we can do and what do you want us to do, I guess its sort of involving them in everything I suppose which I think is slightly different from, you tend to do that a little bit with older children but not to the same extent when dealing with adolescence and by adolescents I'm talking about twelve. I guess rights and consent they're the thing you start with and if you do that right then your patient *is well informed about what's going on all the time"*

D: "Especially when it's their right to know what's happening "

S: "That's right and you always come up with the problem of confidentiality and whether or not to share information with the parents or guardians"

D: "That has to be done case by case?"

S: "it does and I think we tend to be upfront right from the beginning about confidentiality issues I would often say things like there are things that you and I can talk about that are confidential and remain between us there may come a time when you tell me something that may give me grave concern for your safety and if that were the case I may need to share it with your parent but I'd never do that without talking to you. Because if you have a thirteen or fourteen year old that's contemplating suicide then that's probably information that you"

D: "need to tell"

S: "I think the thing with confidentiality is to be upfront with it and say the things you can and cannot keep confidential, one of the traps that people sometimes fall into is to promise not to tell. That's a very dangerous thing to do"

D: "Your legally bound to tell if its.."

S: "no you're not actually"

D: "at some point though, if it's some danger to somebody's life?"

S: "Oh, it depends on the case, but under the privacy act you don't have to tell anyone anything really, and under the guardian act you don't have to share information about a child as well if its in the interests of that child or young person. so the parents aren't automatically entitled to information about that child or young person."

D: " The privacy act has changed its a lot more strict now? it allows for a lot less information to be exchanged between people?"

S: "I don't know, I think that the privacy act you can interpret in different ways. The most important thing is that it does provide a very strong protection for information to stay with that person and not automatically being told to relatives or guardians. But on the other hand a lot of people over interpret it, it doesn't mean that for example if I knew something in my private practice about a patient and I'm concerned about it doesn't mean that I can't ring up a hospital specialist and talk to them about it. People sort of over interpret it and don't share information appropriately because of the privacy act. You are allowed to share information if you do so in a way using that information in a way that its supposed to be used putting a persons life at risk its appropriate to go and consult with another specialist or professional. I think it's a very useful act and I think you can use it as you wish. I guess in dealing with young people and adults we take for granted paediatricians and other doctors might not think about and that is privacy is very important, when they see a young person you should see them on their own. We will start to see them, we will see them with their parents and say this is who we are and this is what we do and have a general chit chat to start with and then we'll separate, one of us will go with the young person and the other social worker will go and speak with the parents. And the same should happen in hospital the young people should have a chance to be seen alone not with relatives and adults there are not comfortable to share stuff with *family there, that's one of the difficulties that we have with the hospital set up of four bedded rooms there's not much privacy you can hear what people are saying next door It s quite difficult really so privacies really important and talking through for procedures as well. Ah what else, the other thing I think is really important for young people is peer support to have kids around that are of a similar sort of age it really helps if your going through a really difficult time if you have young people around you who have similar difficulties or even if just of the same age it would be really nice it would make a difference"*

D: "Your quite lucky in some ways that you have got such a large population "

S: "Yeah and I guess the other important thing is that we've probably touched on already is that whenever young people come to the health system its important to broaden your focus, its a young person with cystic fibrosis not a cystic fibrosis fourteen year old so they come in with all their educational needs and their sexual health issues and they're beginning to think about those so if they come into a hospital like this you have to be able to provide them with some educational continuity if they are stuck in here for a couple of weeks and if links need to be made to other services"

D: "I guess that one thing that I could do, is that a lot of things that people should know about get forgotten because like you say your so busy focusing on the immediate, the broken fracture or the whatever"

S: "the other big issue which I haven't really thought about is disabled young people, including mentally disabled young people, I think that they miss out even more, because you look at them and think that they won't understand what this is we'll just treat them like a four year old anyway. and I believe that's inappropriate if you have a thirteen or fifteen year old with cerebral palsy an intellectual disability they should be treated and given the same opportunities as any other fifteen year old, this is my personal belief, this is going through the hospital statistics for the last year on where all the young people end up and in which services and there was one young person who spent about three weeks in a geriatric ward for respite care and that's totally inappropriate that was probably an intellectually disabled and physically disabled young person in a geriatric ward"

D: "that's really tough"

S: "Yes it is isn't it, and we also get sometimes because we think that the people don't understand or the families don't care we get you know 16 year olds who are intellectually disabled referred to the paediatric services"

D: "that's one thing that I have heard, that there is not a clear distinction as to when the person goes into a paediatric unit or an adult unit at the moment"

S: "No there isn't, its a bit fuzzy there, what we have at the moment is when on their 15th birthday they go to the adult services, if you've got an acute problem"

D: "Right"

S: "But if you've got a chronic problem and a paediatrician looking after you can stay on a bit longer. But what I'm saying is that its inappropriate for a 16 year old to be stuck on a ward with 2 year olds, its insulting to that person and insulting to their family, it doesn't matter if they IQ is well below average, they should still be treated the same as all other 16 year olds. Um one of the *difficulties because we have child's and adults is the problem of transition from child to adult and its especially a problem for the kids with chronic diseases because often what happens is that if you get a patient whose a particularly problematic patient, you don't get on with the family or they have all sorts of problems you refer them quicker"*

D: "Yep"

S: "and they get dumped, so you refer them to an adult outpatients"

D: "where their needs aren't met?"

S: "yep, if their a family that you do get on with then perhaps you might hang onto them longer [laughter] what really needs to happen is to have a proper transition process where you might have one of the nurses take them to their first adult ward visit, to show them the adult wards and where they're going to be and which nurse and that kind of stuff happens you know 6 months before you hand them over so they're not just dropped into a clinic because we know [end of tape] actually I think it was a study and it was looking at young people who came into hospital they had access to a computer and it was like a.."

D: "Starlight, Starbright"

S: "I don't know, it was actually a questionnaire based on a computer, and they could do this thing and it would ask them all kinds of questions and they could answer and it was all confidential and at the end of the programme the computer would cough up well you've answered this that and the other these are the services that might be useful. and what they found with the computer based stuff was that adolescents responded to it really well because it was much more confidential and it sort of fitted, whatever came out with the answers and these days they use computers all the time so any way I looked at that and thought it was a good idea "

D: "It wouldn't be so hard to set that up either would it?"

S: "No, no, and if you had something at the end of it and printed out something it would be quite useful"

D: "especially now that there's all sorts of groups on the Internet as well"

S: "Mm mmm yeah that's right"

*D: "**What about recreational activities and games and that sort of thing?**"*

S: "In the hospital?"

D: "Yep for adolescent people rather than children"

S: "um you mean to have something set up here for them"

D: "you have a pool table don't you?"

S: "I don't know, not down here, no, in the starship there's a pool table but that's, um I don't know what type of recreational things, it depends on the type of patient mix you have as well. I was talking to them in a youth outreach team and he was saying that he's got this dream of, because often you meet young people and they don't like the face to face eye contact, well a lot of them don't in particular troubled lot and his thing is to have a car clinic, because he's into fixing cars and motorbikes"

D: "so people can tinker away"

S: "yeah, so you have all these old cars wrecks [laughter] and you get the kids along and you tinker with cars and he just works along side them and you get a lot of good talking over that kind of stuff"

D: "Its quite useful to have something where people are focussing on something else and not themselves"

S: "yeah, yeah and the same thing happens if you have youth workers going out to play basket ball with kids and that kind of stuff, and I guess that's why some youth and adolescent services have art creation people who sort of get young people involved in art while there in hospital I guess that works the same sort of way "

D: "so people feel like they're doing something"

S: "I think that a resident artist would be a really good idea, if you could get the money, and I think that that would work really well for adults as well but wed have to get money from some other source I think "

D: "There probably is, I mean there's money around in the health research area"

S: [giving over of information from the specialist to the designer] "that's quite interesting it talks about having a regular teenage group on the ward so they get together and talk about issues and um "

D: "have lots of conversations"

S: "and they have um , like the regular members would be the ones who had chronic illnesses and they bring in the kids who have had much shorter stays and they come in as well. The other thing that is probably important to involve young people in is to involve them in management as well so that that if and when we ever set up an adolescent ward or even if were ever looking at getting close to planning it I think we should have people involved in management sort of management steering committee because they will have ideas and issues that we'll be asked to think about "

D: "also the latest things, it's quite hard keeping up with the latest "

S: "Its interesting the questionnaire there, the sort of things that young people want in their ward and all the TVs and Playstations"

charge nurse-adults' ward

D: "the first thing that I've been asking people is the sort of numbers of teenage patients that you would see on average, that you would see on a ward?"

N: "Um it would actually be hard to say. I'd imagine, we've just had the cancer society in contacting patients, I would imagine something like 30 or 40 a year."

D: "That's covering haematology and cancer? "

N: "and oncology and haemophilia mm yeah, so yeah there certainly wouldn't be any more than that, yep"

D: "and the length of stay is the other question?"

N: "ah we're an outpatient department. So, ah we don't look at length of stay. As hospital stay, we *look at it as disease trajectory - how long is the person in our care for, and often that could be years. "*

D: "ok"

N: "it's hard to get discharged from a cancer centre [laugh] so we do at least 5 years follow up so."

D: "so as a day patient, they would come in here to get treatment?"

N: "Yeah"

D: "and would that take a couple of hours or more?"

N: "ah it can take, it can take sort of a twenty minute appointment through to an eight hour appointment, depends what were doing. If its chemotherapy, blood transfusions, platelet transfusions that would take more time so you are looking at least half a day. If it's just a simple injection of a factor 8 for a haemophiliac, or pain relief, that doesn't take quite so long, It really does depend, sometimes people will just come in for reviews or follow ups. So they actually might be coming to have a blood test, see a doctor and check that everything is still well- that they're in remission and then go home again. So that could take 20 minutes so it really does vary depending on what were doing".

D: "but most of them would have started with a hospital stay?"

N: "no not necessarily, um treatments have changed so much over the years and ALL, which is commonly reported as a childhood leukemia, but many adults right through up until their 80s get it. A very serious leukemia, but highly treatable. And whereas 5 years ago you could be hospitalised for months getting your treatment, now you can have treatment exclusively as an outpatient."

D: "is that, you would perceive that as a big improvement?"

N: "Yeah, yeah, yeah, yeah. Well I think, for me, it keeps cancer in perspective with life. So it means there is a possibility of still going to school. It means that at least you're still going home and your friends are visiting you at home instead of in a hospital cubicle. There is some normality amongst… um.. I mean, obviously being diagnosed with leukemia is a really major thing to happen, but some things are normal. Like you know if you're frightened or you feel nauseated or sick. Its actually nice to go home to your own bed um to go into an unusual hospital ward where you don't know who's going to be sharing a cubicle that night. Yeah, so I do see it as an improvement. One of the things um sometimes you get so that you do always assume its an improvement [smile] and particularly with young patients um A couple of times I've been surprised where someone's sort of said they want to stay in hospital and the reason is that they don't want to get up each morning to come in, they'd rather sleep in and stay in bed [smile] than have to actually get up and make the trip into the hospital, even though they prefer to be home. Its actually that getting up early and coming in that's really difficult. So it really does depend. Its very individual, yeah, yeah, each stay is very different. So where are we?"

D: "number 1"

N: "ok, um ***problems and challenges?*** *um oh well the biggest challenge I guess in dealing with teenage patients is whether they identify themselves as a child or as an adult. We try really hard to be sensitive to that and when people are diagnosed with cancer in that, um, in between age group. So if they're 15 and, you know, a tall bulky boy who obviously isn't, doesn't, look like a child, we* *will actually ask them and say, you know, where do you want this treatment to be? Do you want to be in paediatrics or go on to , um. But, no matter what the person chooses some people identify as a child at 15 or 16, um, some people identify as an adult. And its really difficult, and even if a child identifies as an adult, their parents don't necessarily concur with that. So it can be very difficult, um, child going through a very serious, life threatening illness, and the parents want to protect them and be a full part of the decision making process. And initially that's ok, but as time goes on people get confidence, and as a teenager you develop confidence and think well that's fine I can have my treatment and go to school or and go out and party at night or, and drive a car to and from treatment, um. That seems a reasonable enough decision for us to make, but the parent may actually miss making those decisions and often wants to be very involved in that decision making. So its also difficult sort of privacy issues. I mean sexuality, all those things. Its really hard when the parent wants to have a hand in that. And as an adult oncology nurse I'm very happy dealing with the individual. You know, I'm happy dealing with a 15 16 year old, ah and giving them the information they need. And sometimes it is harder incorporating the family because the teenager themselves doesn't necessarily want the family to have all the information. So it is hard yeah, and I'm sure really hard for parents. So I think that that's the biggest problem or challenge. I think that particularly adolescents don't have, don't bring with them, any resources into this. So sometimes it would be easier if they did identify as a child I think, um. In particular things, I looked after someone not very long ago, who, um, was diagnosed with a severe haematology condition, and actually married very young. And his support person, who was his girlfriend, major support person, they actually married very young, and so in terms of resources you had someone who was strongly committed to him and working on his side, fighting on his side for everything. He was ah, um, he was ah, um, that was his strength and a big resource that he brought in. But, on the other side, every time they had the possibility of time out from treatment, time out from hospitals, you know, you'd often say to him, well why don't you and your wife just get away and go somewhere? And they're sort of like, well, how are we supposed to do that? We don't have any money, um. They don't have friends who have houses, you know. Where as when your dealing with adult, perhaps, who are in their forties, they have their incomes, they have their houses, and they've set aside a little bit of money in case something happens. And so they have possibilities because they have resources. Whether they are financial resources, whether they're sort of social resources, like groups of friends who say, 'look don't worry, we'll take the kids" ,um "no problems at all you guys, get off" or "why don't you go up and stay with someone". Teenagers don't have, ah, that kind of organised life. They haven't sort of thought, well something might go wrong, lets sort-of-put a little money set aside, lets make sure we have these things. So even for me as an adult its really hard sometimes suggesting something that is useful um, in terms of actually taking time out, ah, looking after other aspects of their life, because they have very little resource. And so we do sometimes have to be quite creative in terms of making sure that they're hooked in with the social work department. That they are aware that the cancer society has things like, um, ah, some benevolent grants. Some special grants put aside, um, that you could develop a case for to say "well we need money for this, um, yeah so, those sorts of things, I guess that I find the hardest um "*

D: "you said bringing things in. Did you mean bringing things in that they could actually do while in hospital?"

N: "No, no, just resources. The sort of strengths that adults have. You know, as I said, social, financial, those sorts of resources. You know their ability to, um, to change certain aspects of your life, to incorporate their illness. An adolescent doesn't have that. Teenagers don't have that ability"

D: "so the impact of the illness would be sort of greater?"

N: "well, yeah. It certainly becomes all encompassing. I think it certainly does become more encompassing, um. There's also a sadness for adolescents. That's always a challenge. You know, you're very aware of what, particularly 'cause adolescents, particularly with school, its very structured and you know what someone should be doing, and what should be possible at each age group. And if those things aren't possible because of illness, then you know that someone working with them. You do feel a sadness that, um, that even with what we can do here, we can't make everything possible. And, um, although we do try very hard to make things happen, um, you know, graduations and exams, you know really really watching the pressure. People put themselves under pressure to keep up, on exams even. Though so much has happened that year for them because they need to keep going though those milestones because their friends are going through them. Those sorts of things can be hard to watch as a staff member. Yeah, ***problems or challenges****, I'll let you know if I can think of any other ones, but those are the main ones. Resources is something that I feel quite strongly about.*

D: Can you describe any information, concepts or ideas that you can think of that you have found successful in helping patients with any of the problems that they face?

N: Ah well information. We use a lot of written information. We use, we use other patients' experiences. So we always allow someone the possibility of talking to someone else who has been in that situation. Ahhm. We use written information an awful lot too, so that they can get a picture in their mind. Because cancer treatment lasts for such a long time, um, you know. If it lasts for 6 months they're sort of going to need to know what they're going to be doing for six months. So we try and plot things out for them so that they can see where they're going or what's happening. So we give them information on their drugs and the side effects, um, books on how......"

D: "Is that the information that the cancer society gives out?"

N: "that sort of thing. Those sorts of things. We've got some of our own, but those sorts of things, um"

D: "would it be possible, just a bit later, to have a quick look?"

N: "Yep, yep, and um ***information, information,*** *yeah. So those are the main sort of written ones. And we spend a lot of time talking to people, making sure that they know where they're going and what's happening ,um, in terms of resources. We use Canteen plus and Child Cancer Foundation a huge amount because they actually accept people right through to twenty. But the reality is, if someone is diagnosed with cancer as a child, then they will continue in paediatrics right through till they're 17, 18, um, because that is what they know. They're familiar and comfortable with the staff. If someone's diagnosed 15 or 16 then, even though they could go to a paediatric area, they actually often choose to come to the adult area because they identify themselves as adults and also because their treatment and follow up is going to be over another 5 year period. So they are going to have to change very quickly into another area. So we do use the resources that those staff hold and the child cancer foundation and, yeah, CANTEEN a lot, um. We also have our own psychology,* *department of psychology of medicine, and we use that an awful lot. And we make sure that people hook in with someone that they identify with, ahhm, ah, often just for assessment (but also) say that they do need some help, some counselling, support or hypnotherapy, things like that on the way through, they do know who it is that they are going to see, so its not such a big deal at the time. It means that they go and see someone they really know, um, our social workers also are counsellors and so they become a big part of the treatment as well. So its really a whole team thing. So, and that's a big part of our resources, um. Activities are really hard. Apart from CANTEEN, which does it very successfully, um, I see the informal activities that young people do together. So that, if you have 2 people, well you know young people as lymphomas, um, you can see that their interaction, you can sometimes see that a young person with cancer is quite isolated. So they might see another young person in the day ward and recognise someone in their own age and you can see that they're actually relieved to see that their is someone there their own age. They don't necessarily all mix together though, but you can see them recognise that, and sort of think "ok I'm not isolated with this, I'm not the only person this is happening to", um. But, in terms of actually getting them to do something together, it doesn't actually work like that, um. They bring in their own support, or they choose to isolate. But they don't, you can't just throw a group of teenage kids, patients together and say "there you are going to get on" and do sort of therapeutic work together, um, unless there is someone to facilitate it. It just doesn't happen. So we don't have support groups as such, Also, sometimes 'cause treatments so important, and your very vulnerable in the treatment center with your doctors and nurses. Sometimes its actually nice to take it outside the treatment area, provided there is support. Somewhere else, so that's where the cancer society comes in. So some support is really, um, yeah, um, So I guess the sort of activities thing is really hard, um. You can suggest a hundred things later and they don't want to do it. They want to do what their peers, what their friends are doing. And we spend all of our time trying to make that possible. I mean, if there is a physical reason they can't do it we try and fix that. It might be somebody's platelets are low and we've given them platelets just so they can go to a dance because that's important, um. It might be that again a financial problem. There is no point suggesting what you can do. You have to put some effort into saying, "well, ok, if you had the money you could do that". And very recently, um, Rotary was involved with the cancer society and looked at the possibility of raising some money. But again, they wanted to look at raising it for the group, as group assets. And we were saying, its really very difficult. What you need is a fund where you could individually .."*

D: "draw on it as you need?"

N: "apply to the fund and say this is what's happening for me. This is what I want the money. You know I've applied to these people and I can't get it, um, can you help me kind of thing and perhaps have trustees. And so we sort of looked at all those things and we still came back to individuals. That people don't want to do things as a group together."

D: "its a very diverse, I mean obviously I mean its every different type of person that comes through here"

N: "yes, um with, well only cancer and haematology patients come through here. That's all, um. We don't use schools or anything. We don't really use the hospital teachers or anything. They're too, they're too old for that, and, um, I mean, if someone's still in exams they either go to school or their teachers provide work for them, or they have some correspondence arrangement. But we don't *tend to get involved with schooling and we don't liaise with the paediatric school room. We only did that with one patient. And in actual fact, I didn't find it was that easy because, um, they would all bring videos and games and stuff down, but they expected us to have a staff member to be free to interact, and we actually can't supply that. We just can't supply a registered nurse for that all the time. So, um, it wasn't easy, um. I think what happens in the school room is great, but its not easily transplantable around the hospital, yeah, ahhhhmmm,*

D: have you any suggestions as to what would be helpful to include in a resource for adolescent patients?

N: um, I think we do need good publications. I think that you often need publications directly related to adolescents, you know, and at adolescent concerns um. Um, and I just spoke about you need some sort of fund, yeah, that their needs are so diverse that I actually think they do need something that they can draw on. That there is people to help facilitate what their wishes are but they're not necessarily, yeah, forced into group activity. I think those sorts of things exist really well. Things like CANTEEN for us in cancer work. I mean its fantastic. We couldn't ask for anything better. And I know with haemophilia patients, we don't have a group as such, well we do have support groups, they're actually for families, (family groups rather than the individual). We do have things like camps and that works really well. But I think that that sort of things been set up, but its the individuals that aren't addressed. I think the group stuffs been addressed, but the fact that people (when they're not at a camp, or they're not at a CANTEEN group) they exist as individuals, and they have problems and needs.

So that would be my main suggestion for that."

charge nurse-childrens' ward

N: "...addresses those of adolescence, several other people over the time have talked about different modules of assessment of adolescence that can help you address all the.."

D: "key issues"

N: "Yeah key issues for adolescence. So part of the assessment . There is an adolescent assessment as well, so you don't forget about their..."

D: "family and peer group."

N: "yeah, and those sorts of issues, um. And even in terms of presentation and art work, I think it needs to be what they want and use. What they really like. Rather than us trying to make up our minds what they really lik,e um. One of the past on the ward where I was previously, and we moved the whole ward. Picked up and left and moved here. On our previous area we actually had an adolescent kitchen with a dining room table, a few chairs and cooking equipment and things. And that was really what they wanted at the time. So that's what we did. So we gave up a room so that they could so what they wanted. So that they could keep their own fridge there, and keep their own food there. And they had a TV so that they could watch TV later than the other kids (cause they were adolescence) and, um, I think that that really had a positive spin off. Because I think they knew that we cared and that we viewed them as being important people, and that their views were valued, and that we were listening to them. Since we have come up to here, we have had less space and we haven't been able to give them an adolescent lounge - just because of the room restraint. But we do have an adolescent lounge that they can use um. We try to keep one part of the ward for *adolescence so that we do not keep screaming babies beside adolescence. But sometimes it goes out of our control and we have got no choice but to place them there because of constraints of our design, our ward design. But I think taking those sorts of ideas into account will help these patients. Does that answer your question?"*

*D: "**Yes. Are you aware of any publications that are available for use in hospital?"***

N: "Um, we have quite an active school system, and especially for our adolescents, we have a high school teacher who visits the adolescents, with needs, um, for education on our wards. And she puts in place a programme in liaison with their school or correspondence school so that they can continue their programme of learning. And she has resources such as a computer and books."

D: "so the patients can get access to a computer sometimes?"

N: "Yes they do, and they actually have a computer down in the adolescent room and they have access to the Internet down there."

D: "oh really?"

N: "and they are at present looking at designing a web page, at present, for the adolescents"

D: "that's fairly exciting"

N: "yeah, it is. We have talked about having a news letter or a sort of monthly bulletin, something that is produced by the adolescents for the adolescents. And the teacher has been keen to get that going. But I don't know where that's up to. But we've been encouraging the school to do something along those lines, because often the problems adolescents have are shared problems and they can gain quite a lot of insight through sharing."

D: "or even just knowing that someone else has gone through something similar."

N: "Yeah. Yep, um, activities. Um, as I said, we've got an adolescent play specialist and he visits the adolescents sometimes. He might just talk to them. Sometimes he might bring them things to do. Sometimes he might take them out and do something with them. Sometimes he'll get videos that they request. So he doesn't have a standard programme. He tailor makes the programme to meet the needs of who he's got, and what they feel would be usefull. I think that's really important, to find things that people would find useful for them. Um, and there are a few publications around but they don't come to mind at the moment. There's something called, oh I cant remember what its called, there are a few sort of handouts that we give out."

D: "is it something like this sort of thing? [teenage hospital guide]"

N: "I've seen something similar to this. And the youth service have some things. Sometimes they're related to sexual health or those sorts of things that are around the place. And also giving, letting adolescence know what their rights are, and their obligations, and how they can, you know, get a fair treatment while they're in hospital. So we have lots of publications"

D: "like the health and disability services booklet?"

N: "Yeah, and those sorts of things. And just knowing that there is legislation around. Getting fair treatment and access to information. Privacy, confidentiality and those sorts of issues. Because they are really quite important one for adolescence. Have you any suggestions on what to put in a resource for adolescents. Well, you know, that little book that you just showed me there. Something *like that would be really useful"*

D: "that would be useful?"

N: "yeah, I think it would be, um,"

D: "I was thinking of something along those lines. But maybe, if I sort of talk to some teenagers and get something that looks much more 'up beat' and much more interesting to go through."

N: "Yep, yeah, and maybe for teenagers who are in the hospital rather than those visiting the hospital."

D: "Oh, yeah, yeah."

N: "But, um, certainly they, um, like to have input too. That's something else we do, we encourage them to write letters if they don't like something."

D: "Oh OK"

N: "or if they have ideas that we can't "

D: "Who do you encourage them to write to?"

N: "I encourage them to write to the General Manager or to the Business Manager to express their ideas so they actually have a "

D: "would it be a terrible idea to put that formally in a general resource?"

N: "No, I don't think so, I think that if the've talked to the charge nurse, or to the person who's in charge of their unit, and if there is no funding or support that can be given to something of the "

D: "so maybe a little note to say, if you think of anything ask who to "

N: "yeah, I think that it's really important for adolescents to"

D: "have a say."

N: "have a say, yeah, and make upper management aware that "

D: "they exist.

N: "yeah, and that they have got ideas. And that they want to have an input and a say in how decisions are made. Because I know that we've got one young man on the ward and he sees the Business Manager from time to time. And he asks, is it possible for this, and is it possible for that or you know. And then its always on her mind and then she thinks, oh well."

D: "and if some funding comes up?"

N: "yeah, maybe we can shoot it that way or a little bit of space comes into lots of space. What can we use it for? I know that the adolescents want such and such. Maybe it's something that we could be considering. So advocating for themselves as well, because, you know, sometimes I think that the, um. There's a, um, perception that nurses want a lot of things. But I think when a consumer states that they want something it's "

D: "more powerful?"

N: "yeah, much more powerful."

D: "I wouldn't imagine it happens all that often either."

N: "no, that's right. I know that when the adolescent unit closed there was a large delegation of protest and there was a lot of lobbying to management as well as MPs and various other people to see if they could. And it really, there was quite a spirit of comradeship. And you know together we can get to anything if we really put our minds to it. "

D: "but it wasn't enough?"

N: "no, it wasn't enough. The, I don't think that... the thing was.."

D: "its sort of innovative I think, that thinking about adolescent care is still too innovative in New Zealand, so it gets the chop first,"

N: "yeah, that's right, and often it's an area that they don't actually perceive a large benefit of having put a lot of money into,"

D: "its strange though, because they are the future."

N: "Yeah ,and everybody goes through adolescence."

D: "and its really quite a pivotal time for quite a lot of people, I think."

N: "Mmm, yeah. But for some reason, I don't know, it just seems like its not valued."

D: "because they don't have any money."

N: "Yeah, I think you're probably right. They're not earning. They haven't got votes, and often they don't have the skills to market themselves, or to present themselves, or to advocate strongly enough for themselves, cause they've not quite got there."

D: "confident or "

N: "yeah, and they don't have those communication skills, yeah. So I think that having a united voice is very powerful stuff. "

D: [interruption phone] "What did you imagine I was going to be doing when you first heard about my project?"

N: "When I first heard about your project I thought that may be you, when you were talking about the resource, that you were going to develop . I thought that my perception was that, maybe you were going to have some sort of manila folder with a turned up edge, and that you would have some stuff that sort of explained what the hospital services were, and what was specifically there for adolescents. And then, maybe, some other little pamphlets, like looking after yourself or keeping yourself safe. And, um, what your obligations and rights are. And things might be and you know just some brochures that you could whip out to look at and um. And also a feedback sheet to say how they'd found it and what sort of things, ideas, that they'd have for "

D: "feedback sheet to whom?"

N: "to um, that could go to whoever was coordinating the adolescent packages so they could, um, give input. Not what information was in there and what else they would like, or what wasn't very useful so that they could "

D: "and would that sort of thing be really useful?"

N: "Yeah, I think it would be. If you had something in their lockers and when they arrive that told them about . But no, we have found peer and information folders that are in the, um, rooms *and they have sort of, information like, welcome to the ward and ,um, health care team."*

D: "more and more places are putting together information for themselves like that"

N: "yeah, and so these ones we've put together for our ward, for our families. But they are more..."

D: "for the parents?"

N: "yeah, they're more for the parents really."

D: "but they would cover a lot of the basic information. "

N: "Yeah, they do. Like the school, and the therapy services and the dietitian. So there is some information here that would be useful for your resource package, but maybe just some adolescent stuff that would be useful if it was specifically "

D: "catered to their needs?"

N: "yeah, what's there to do, and what's out there that you can access."

D: "yeah I'm just beginning to learn about some of the key community groups."

N: "yeah, so I think that that would be really useful. I can't think of anything else."

adolescent specialist

S: "the first question, can you describe any problems or challenges that you have had in dealing with adolescent patients.

I suppose from my perspective (for young people who need to be in-patients in hospital) its not the other people that are a problem, its more the system. So the system is not oriented to meet the needs of young people. The health system in New Zealand has traditionally had inpatient services and secondary health care providers that have child and adult services and the cut-off age has been 15. It's been historical, and it doesn't in any way take into account the developmental needs of young people. So, if we look at adolescence as a time between childhood and adulthood. And we recognise that it generally starts around the age of puberty (or may be earlier for some young people) but often early adolescence would be around 11ish 10, 11, 12 -something like that, and finishes in adulthood - which has been stretched up further and further. Certainly most people would recognise it as the early 20s, most people would go into adulthood. So they have a cut off point of 15 when they are homeless. Which means that some adolescents are inpatients with children, some of with older adults, but there is nothing in their environment that is supportive of their developmental stage."

D: "the developmental theory, is that still based on Erik Erikson?"

S: "Well I think that it's moved a long way from Erikson. Erikson's theory was around identity formation, and while that was something in that, I think that was inherently [interruption phone call] so back to Erikson"

D: "so where is theory at now?"

S: "so I think Erikson, when he talked about identity, it was inherently around crisis. And we know in fact, that in the 70s there was a lot of work by Rutter that looked at the normative development of adolescence that said that actually normative development from an adolescent perspective wasn't full of storm and stress. I think that we've now come to a more balanced perspective. Yes there are *some difficulties for some young people, but for most young people they see it as not a particularly difficult time. But from a parent's perspective there are more problems. So parents are the ones often who have the more significant impact of adolescent behaviour, because they are witnessing and experiencing the transition of their child to an adult. Whereas they see the morals and values of their previous child's behaviour as an adolescent conflict with their morals and values. Whereas for a young person it is quite simply their choice now, and their rights to make some decisions and their way in the world, so they don't see that as a problem. So modern theory would hold it - that yes, they do see information as important, but also other conventions and relatedness between young people and their parents and um….."*

D: "figures of authority?"

S: "Eeow ah, not ah, I don't necessarily think that relationships with authoritarian figures is more important than people's well being or the quality of their connections with family, school, neighbourhoods and culture. Are the four major groups of young people's environments and connections between those other people, and its not only connections, but having connections, but the proper use of the connections."

D: "Some of the things that are more specific, some of the things that I have been touching on the edge of in the readings, are of adolescents being in crisis or aware of their body not performing or whatever is that? is that……..?"

S: "I think in my experience of young people, especially early adolescents who are in hospital are that they are very conscious of body and self. So, you get pockets of, …but I don't think there is as much of that in later adolescents or adults. You know, they are probably used to it. Once they have gone through that body change which is often in early adolescence -a pubescent type of thing. I think, yeah, people are quite aware, and people should take account of that…. which is difficult for providers when they are used to a child where it doesn't matter so much. Though people, once again, should be respectful, and we hopefully are, but there is different types of issues in being self aware"

D: "what about some things I have touched on such as non compliance with treatment, withdrawal, non communication that sort of thing?"

S: "Yeah, often. once again, as I say, we are the problem. Our expectations as health providers of young people is often at complete odds to what a young person wants and thinks is important. In fact their very definition of health might be quite different. Young people do not necessarily perceive things as health problems, they might suggest solutions and answers where we might find problems as adults and as health providers. So we have very different ways of looking at the world"

D: "So quite often it's a case of educating the nursing staff and doctors."

S: "Its reorganizing the system to appreciate and be respectful of adolescents… to what their needs and their perspectives are. At the same time, there is keeping our knowledge about health and health issues and certain diseases or whatever and treatments up there. I'ts not enough just to know about how to treat a disease, for instance, if we don't take cognisance, and aren't aware of the other developmental perspectives, or their emphasis. So, for instance, a young person has severe asthma …what is a possible - its not enough to use new drugs and go on about the technique, do physiotherapy if that young person's psychosocial issues are all wrong and they're disadvantaged *and there is abuse, violence. Where they're dropping out of school, they're beginning to have difficulties or trouble with their friends. You know, just looking at where all we are worried about is the actual medical aspect of their health. So at the same time, it is not going to work if you dilute the consistency, and you let the parents to do all the caring of the adolescent, as they need to know that responsibility… at the same time you don't want to hand them all the responsibility of a young adult and alienate people from their peers. So it's a balance with the person, with their developmental, psychosocial issues, in addition to the medical knowledge. So it's really taking a far more holistic perspective on the young person. But we know that the results are better afterwards, that there are some benefits that if we do that we also that the outcomes for young people are respectable, their health outcomes are better, their stay in hospital is shorter, that it costs less. So there is a lot of positive, yeah well, there is a lot of good stuff that we can do when we address these things. But it's difficult because it means that health providers and health systems have to change and there is, you know, there is a huge immersion in changing establishment. And in some ways, you know, new things are always set up to fail. So they're underfunded, under-resourced, under-supported, and we're not given enough lee-way to learn by mistakes, which is a natural part of development."*

D: "what seems to be happening here? ..well all the people I've been talking to seem quite aware of these issues"

S: "So you need a ground-swell of support, but you also need it up in management. So yeah, its a good idea, but a lot of people here who have come from the street …."

D: "Do you know of any resources that are used in hospital that can help patients?"

S: "Um, in terms of resources do you mean?"

D: "anything, publications, books, articles? I've been shown a few things like cancer stuff for teens with an information pamphlet or sort of flyers or….."

S: " so there is some written information around. There is also other resources, like human resources that are important, like actual people whose job it is to actually work with young people in hospital. Like schoolteachers, and play therapists and social workers, you know, and lots of people like that which are important in terms of hands on resources. There is not a lot that I'm aware of, um, we've probably talked about developmental video which they can see that explains everything. We've talked about having specific activities such as maybe having a weekly round in hospital where young people actually come together and actually connect over something - so they can have a common place to join and mebbe share a meal and …so something…. and there is also a lot of resources donated to the Starship. They had an adolescent ward, but the ward folded so the resources have been dissipated. But they had an adolescent room for the ward"

D: "play stations?"

S: "yeah all that sort of stuff. We have resources here, but ours are mainly outpatient focused...."

D: "Is there anything that you think of that would be helpful to include in a resource?"

S: "Well I think um…"

D: "Would a resource be useful?"

S: "Yeah well, um I think that something could be useful. But one of the things that is true of all resources is that if your targeting a specific group, you need to understand the diversity within *that group. I think one of the traps is to believe that they are all and its not a homogeneous group, its very diverse, so what we need is to so there is quite a diversity but a common start in explaining what happens and what to expect it could be done in written form or video form the people with chronic illness who spend years in hospital they're needs are different. It could be other things which website, could be video or TV or something like that. Whatever, it could be a web page for young people in the hospital, it might have not only information but conversations so that if you were there, you could chat to other young people in the hospital so that maybe there would be other ways of doing it "*

D: "Have you heard of the American starlight starbright project?"

S: "Ah I've heard of it, but I don't know a lot about it"

D: "anything else that comes to mind?"

S: "The other thing is that a lot of care and group support (is necessary) which I think are a good support for young people in hospital, in the sense that adolescent health in Melbourne has a common endless peer support group that are aware. (This) might be useful for you. It's in Melbourne, the children's hospital there is one in Sydney, there is lots in the States and they are setting one up in Perth. The development of resources for young people is a major undertaking. What do you want to do? What do you want to develop? You can pick anything and just go for it"

play specialist

S: "I'll just put a hot cup of tea down before we get on with it. Now, number one. ***Could you just clarify for me, you say describe any problems or challenges you have encountered*** *in dealing You mean, with the adolescent patients themselves, or in terms of a staff member having to deal with that patient load?"*

D: "Both. Start with the adolescent patients themselves."

S: "O.K. Um [sigh] for me personally, I've done quite a lot of inservice, and ,ah, and the challenges in terms of that are not so great as the patient load that I'm comfortable with, um I think that, um working with them in children's ward creates stresses and issues that eventuates it so that the normal adolescent behaviours often get acted out by the situation, and that's probably the most difficult."

D: "Can you give us an example, is it? what sort of?"

S: "Well. I think. Um. you know. because they have no personal space they often create space out of corridors. Or their noise factors, they push their noise levels up (which is normal for them) but in the next room there is seriously ill children. And the two just don't gel and so invariably its the adolescents that have to pull back so they will feel that.."

D: "resentment?"

S: "put upon, Yeah and justifiably so for those situations. I think the problems in terms of a staff member and a service co-ordinator is the same issue that we often have to put them in situations that we know compromise all of the things that we know they need for a positive health encounters. It is very rare that they can have personal space. They're frequently in with people who are not an appropriate age group so, like in older people or young children for situations. The resources, I think in terms of providing resources for them that they are opportunists in taking *resources [laughter] and that's probably because there are so little. So that when they get older they hang on to it. Um I think."*

D: "For example, can you give me an example?"

S: "Oh yeah. I think they push their limits and so like play stations or anything like that. They, and either acquire them and in doing it they will take the things so that it meets their needs, and not necessarily thinking in terms of the wider needs, um, the ,um, the limited resources that we have."

*D: "**What sort of resources do you have?**"*

S: "Um, we're probably not too badly , prepared. We've got playstations, CDs. We've got key boards, we've got a whole schooling system of course, but apart from that in my service But we've got, um.."

D: "And they're for the whole ward? Any one can use it anytime?"

S: "Yeah, but you know, that we're starting to build up resources like book resources, creative resources, video resources, pool table. So we've got the resources. But once again, they're all targeted in with younger school age children and babies so they're all mixed in together. Whereas if we take these and put them in an area specifically for adolescents or young people (whatever your terminology is), it would make life much more comfortable for them and easier. Um if your looking back, its like you put a whole lot of young people together in a room you're asking for mischief and you're going to get it. They're a difficult patient loading because, um, when they get bored and they're uncomfortable they will act out and they build off of each other. So they are challenging, particularly... "

D: "What sort of numbers of adolescents would you get?"

S: "Through here?"

D: "Yeah"

S: "Um, we're just working I can't tell you the exact numbers. I probably could, but a bit later. but there's enough adolescents going through this hospital in (the) age group to have about ten beds for the day. Now a third of those will be obstetrics, that's young girls having babies."

D: "O.K."

S: "So. and in the paediatric units we go up to 14. Although its sometimes slides across if young people are in a really inappropriate area else where, then they bring them down. Because, with rheumatic fevers, 15, 16 year olds, I mean sometimes they're up with very elderly people in their 70s 80s and 90s, and we'll bring them down here, but its not the ideal either. Um, does that answer your first one for you?"

D: "Um, yep"

*S: "Yep? um... **can you describe and information concept or ideas that you have found successful in helping patients with any of the problems that they face.?** Um, I think that you need to be very honest and have information and be prepared to share and do it. I mean, currently this service is three years old, our play and recreation service, with hospital play and recreational specialists working here. So we're currently developing resources like, information packs for adolescents, like adolescents coming in that may be having burns or major surgery, having photographs of how* *other young people have done it and what some of their coping strategies are."*

D: "So, specific to each illness, or?"

S: "Yes, to the major things that are going through, and like, we'll sit down with them and say O.K. this is what's going to happen, you know, and work out what coping strategies they're going to do, what's their care plan. We have what we call developmental support plans, and part of that is about You can see by the sheet there, so sitting down and filling out one of those with them and sort of saying O.K. um.."

D: "and which staff member would do this?"

S: "Its one of the developmental support people. So it could be a nurse, could be a teacher. Mostly its a hospital play specialist. And we know that, like it says up there for adolescents, their needs in hospital are working to achieve independence. They struggle with their identity. Who am I? And that's not easy when you had limbs removed and you've got burnt. So who am I, and how am I going to look like to my friends, their physical development. You know and you change things. Their peer group is important. But you know, we also have rules in here. So, having 20 teenagers crashing into here is not O.K. you know? and you know for the older ones they're mostly over 14 as I say are on other wards. So you know, its about building trusting relationships. But does this young person, (because we have a lot of young people who come in here who don't trust anybody) you know, we have a 50 50 split of kids that come in, who have good personal relationships with their families, their friends, and their peers, but we also have young people who come in here who have no self esteem. So we look at it and say, does this young person have the skills for building trusting relationships, and if not, then we need to develop our care plan around it."

D: "So you actually have a chance to help people in an individual basis even more than they will be getting in other places, like that they may be getting in school?"

S: "Yep, yep. So we go through that check list, providing the opportunity to meet developmental needs. Now, if this is a young person that's going to school, he'll continue his schooling programme, either at bedside, or in the classroom with the hospital school teacher and they will interface. I mean, some kids are too sick, they can't and that's targeted supporting self care. And their decision making, you know, its about like O.K.. You know you've got a dressing that's gonna have to be done. Now do you want this morning or afternoon? Nope. That's a choice that we can give. So about giving "

D: "giving as many choices as possible?"

S: "Yeah, you know, and like, do you need someone around you who can support you going through having this dressing change? Do you have coping strategies? Do you know how to balance the pain? Those sorts of things and work those things through, um"

D: "Do they have specific pain? Do they deal with pain differently from other age groups?"

S: "Um, for each person, pain is individual. And its a lot, its got to do with perception. But certainly an adolescent will handle pain quite differently to, um, a young child. And so its about, some kids just want to tough it out, some kids just go to pieces. It depends on what your experiences have been before. So you need to build on that. Some kids are needle phobic. You just have to work on that, and see where you're going and that. Our role as hospital play specialists (is) to put *that in place, to see if they know what's going to happen. Or sometimes, you know that they've got to have 30 or 40 stiches coming out and do they know how to manage that? Can they manage it? Do they want their parents there? Don't they want their parents there? And to work out an individual plan and stick then to it. And a lot of that too is that the individual kids will have special frame-working on them, to go home and to go back into their peer grouping. So their self esteem, you know, they've got this great big metal thing that goes from here to here [pointing to ankle and mid thigh] and you've got to go back with your mates with all those things on. So we prepare them with information"*

D: "So to prepare them that way, is it mostly by talking with them?"

S: "No you can't just talk, talking is about..... I'll show you what we do. So its like this. This is a young teenage kid- had a picked line put in, that's a line for treatments. So we've got a video that shows another teenager going, so its role playing."

D: "Oh great, and that's done, who's created those videos?"

S: "These are play specialists and nurses who are working on information like that. So this is another one, they get an opportunity to talk about it, what they understand. So its a process of understanding, enhancing that information, so that's part of.."

D: "and you can show them the video on the ward?"

S: "Yep, yep, we've got video machines and things like that. So that's part of that process that you asked about in providing information. Um, some of its done by the nursing staff who will sit down and discuss things. Some of its done by us,. Its who has the best relationship with this child and family, who's got the most time and what are the needs of this person. And that's done every morning"

D: "So this here would stay with the patients notes and any one who deals with the patient would be reading this?"

S: "Its part of it. Yep, yep and we chart into the notes, each one and that's done in conjunction every morning at 7.45am - charge nurse, school teachers, play specialists, physiotherapists. We get together and look at the patients' notes and we decide what things we need to know to organise an action plan that's offered."

D: "and what about the teenage people who are on the other wards?"

S: "No, they just get treated like the adults"

D: "O.K. [laughter]"

S: "Tough. It is tough up there."

D: "Do you get requests from those other wards?"

S: "We're not in a position, at this point in time, to actually be able to service that. I mean literally, we're pushed with our resources to be able to do it. But we're aware of it, and we've got an action team going together looking at, um, improving our adolescents and trying to do that, of like putting together, what we're Something, something, creating an adolescent ward via a cluster area maybe. And then maybe looking at having a transition team, so that, if an adolescent goes into a certain area, they can pull on their expertise of us, you know, and the social worker whose *working with adolescents. So that's a fairly new development."*

D: "Cause its a break for some people too - going from the children's wards to the adult wards."

S: "Its the ideal. And its what we'd like to look at. And a lot of energy has gone into that."

D: "It sounds like you're doing quite a lot of child-related work."

S: "Yea, we have, a lot, yeah, a lot."

D: "Its quite exciting."

S: "Yeah, it is. Its really exciting in terms of that. So you know, like we recognise that some young people will have to stay in specific areas, because we don't have the expertise outside of that to be able to duplicate it. But you know, then we would come into them (rather than them come into our unit), and I think that's what everyone's going to have to do. So that's, you know, towards 2000 plan. But at this point in time if you're not in the children's wards then it can be difficult. (The) same in the neo-natal care and obstetrics if you're a teenager. You're developmental needs are not necessarily met. "

D: "I guess we've sort of moved onto the next one?"

S: "Yeah. ***Am I aware of any publications, resources or activities that have been designed to help patients****, um, I think there is very little written in terms of the whole, for children and young people in hospital. The only brochure about going into hospital is done by children's health liaison group, for your child going into hospital. So I know of no publications that are available, and yes there is a need of one, a major project. I think that within hospitals individual activities have been designed, such as I have just outlined to you, those there, for adolescents."*

D: "Who is that available to? "

S: "Well, if you came into hospital, here in this hospital, we would use it "

D: "But its designed by this hospital for this hospital?"

S: "Yeah, yeah. No we haven't. And you need to develop, like, its no good having pictures. From my perspective of how they do a picked line - that may be different in other places. So you need to do it..."

D: "So it needs to be very specific?"

S: "Yeah, you do, cause you need to prepare them for the smells in the place. Like the sounds in the place and how people do it. And then specifically there, so it needs to be specific. So that I think, that going into hospital, and understanding the impact on hospitalisation on yourself and on your peers and your group, and the general type brochure. I've got some here, when I have a chance I'll dig them out for you"

D: "Shall I take a note of that?"

S: "Yeah"

D: "What would you call that?"

S: "Its overseas information, most of it, for adolescents. And there's a need to develop that. If I don't find it while you're here I can send you photocopies of it. Can I have this? [referring to the list of questions]"

D: "Yep."

S: "Are there any patients of that age?"

D: "I'll be talking to the charge nurse about that."

S: "Yep, O.K. I'm not quite sure what you see, in terms of the patient information manual, designed, I mean. I'm happy to participate in any way, in anything that you're doing to make it positive, because I think, that there is little enough resources out there and we all need to help each other. So I'll be happy to participate in any way at any time."

D: "I guess is there anything that you can think of off the top of your head?"

S: "Are you looking at a manual, like this? Or are you looking at a brochure that young people in hospital could understand about the impact of hospitalisation?"

D: "Well, its in flux at the moment because I am actually beginning to talk to people. But my initial idea was, I found the children's manual like 'a kids guide to hospital as a strange place."

S: "Oh yeah, yep and you were thinking about something like that for an adolescent?"

D: "And I was thinking of something like that for an adolescent, but more designed for adolescents. I wanted to make it more like an activity, um, like a series of games and puzzles that you could interact with."

S: "Oh, Righty oh"

D: "But that covers the same sort of general areas"

S: "Um"

D: "So, its sort of a combination of sort just fun activities that are slightly based on the hospital, to dealing with some of the psychological things, like actually being in an institutions and dealing with doctors and dealing with nurses and asking questions and that sort of thing. "

S: "Wow, that's a big project! I have not seen anything like that in all the years that I've been skirting around"

D: "Well you know there is actually guides. You buy them in book stores, guides for adults. 'Your guide to hospital' and they've got um.."

S: "Oh, I know"

D: "just information which is, how to deal with, how to get the best out of, that situation."

S: "Yeah, yep, O.K."

D: "So I want to do something that bridges halfway between the children's books about it and the adult books about it, but does it in a really fun way."

S: "Ah ha, Mmm mmm, I've got that book here, 'A kids guide to a strange place' we just shifted office 2 days ago."

[interruption with other staff member,they chat together for a 5-10 minutes about the latest news on the ward]

S: "If you change your emphasis and design a format that hospitals could take and

D: "So they could put specific photographs in it? "

S: "put specific things in it about, for young people, in seeing what they want. Like what resources and services are available. They're a small niche market in a hospital"

D: "No, I do know, I do realise that."

S: "But I think, you know, to put together a design for, with some activities and things for self esteem and things like that. some work with drawing and different activities that you can use with young people and I think that you basically would be looking at the younger edge of that group rather than the older age group, which is much more specific."

D: "But I thought that the same information, if I could make it look more sort of in keeping with the older age group."

S: "There's some lovely.... There's a lovely book out that's 'what's happening to you, happened to me'. And that's a book for young people with multiple sclerosis. And it talked about, you know, feelings about being in hospital. Some of those feelings, you know, who are the people who can, you know, like some of the questions that you asked. Like a rap book type thing. I've seen that overseas done too. You know, the draft is a rap book, you know, who are the people, who are your peers, what are you in hospital for and there's a whole series of stuff, you know, working with young people over there"

D: "Cause I found a book with a lot of quotes from teenagers - about teenagers in hospital. But that was the 1970s or something like that."

S: "Yeah. You know, I have a booklet about teens in hospital if I can find that for you. I can just photocopy it for you, from overseas. And it just talks about the issues for young people in hospital, you know, privacy and that. And how to achieve some of those and that would be good information to adapt and put into it. And the other would be, you know, if you did that as a format that other hospitals could take and add into it. I could see some practical applications whereas, you know, a kids guide to a strange place was an overseas book. And the Americans tend to buy that and do that with their children. I mean there's been several attempts to do it in New Zealand"

D: "For children?"

S: "For children. But they all go cartoony or use animal themes and they just don't work with children of this day and age. will I believe. And the other thing is that people want to do it as a colouring in and kids don't want to colour in like that when they're in times of stress they draw their own pictures and things like that. So, I would see a practical application more than the format of a kids guide to a strange place (which has got huge amounts of work into it) but to put together, you know, an information pack. You know, of self esteem exercises and body imagery and understanding the body inside, you know, like a template of the body because many young people don't have"...

D: "like where's your heart and where's your liver?"

S: "Yeah, those sorts of things into it that people, tying into school teachers on biology and that some of those thing, and adapting them."

D: "and also the hospital hierarchy?"

S: "yeah, who the people. Well yeah. Its not quite that straightforward any more, you know. You're talking about skills on how to ask people to help you . Because, once upon a time, doctors were in *white coats and nurses had red stripes on their shirts. Its not like that any more as you'll see as you walk around the hospitals - its much more informal."*

D: "I thought, like you said, if I create something which has a format and has a whole lot of different options..."

S: "Yep, yeah"

D: "Which means you can actually pull some out and put some in.."

S: "I had a training book. It was, um, on um, family centred care, and it was about a whole series of exercises for training up staff for things like that. On asking the right questions, and the terminology, and those sorts of things. So something like that, an information manual that had some exercises in it. Peter may well have some good things"

D: "Especially, I thought, what would be interesting would be, to give the adolescent patients something that helps them to know how to address staff and how to ask questions that they "

S: "Yep."

D: "Or you know ,this is an inappropriate question to ask and this is, you know....."

S: "yep, and you know, giving the information that, this is your body and it is O.K. to ask questions and...."

D: "Your rights and your responsibilities."

S: "Yeah, it is you know. But in a way that's not confrontational. That helps them facilitate it, like you know, the reality is that you have a teenager sitting up on the bed here in an adult ward and saying 'I'm an adolescent, you know, and therefore, you know, my right is to have this and this and this and its like yeah, and you know what's going to happen. (That) is, no one's going to answer his bell and all the rest of it. So it actually has to be practical as well as and it shouldn't have to be like that.... But that's the reality. So, it is about practical things that works from both sides of the fence. And, I think, that's where, if you interface with people in doing those sorts of things, (I wish I could find), the other one is about knowing your feelings inside you know, about the ups and the downs and the bumps and the rolls are normal pieces and who are the people that can help you if you have got questions to ask."

D: "anger, and fear and sadness"

S: "all of those things. The impact of hospitalisation on you, on your peers. I think one of the other ones, is how to stay in touch with your community so they don't get lost. How their community and some tips on how does this community stay in touch with these young people. I'm telling you, the number of schools that stay in touch with young people are very very small after the first two or three days."

D: "really?"

S: "There'll be one big patch of things that come through and then its kind of like we've done it, this is your parcel for the hospital, rather than drip feed it on a daily basis. But having said that, most young people are only in hospital for a very short period of time too. But the long termers, they don't get those, you know, trips from their mates, the e-mails, the follow through. But part of that is our responsibility to do it as well yeah"

D: "what, do you contact the schools?"

S: "Um, well I mean, I think for schools to stay in touch and keep that peer connection going, um, and some of the changes to the schooling system now is about when these young people go home and they're at home not at school. They've shifted some funding from school, so after the first ten days, if you're not only going to be in hospital for under ten days, um, you don't get schooling either here or there. Um but, that means that they're trying to build a service so that when children are at home from hospital, and they are at home in home care, and they are going to be in hospital, or at home for over ten days, then they will get a schooling service at home."

D: "O.K."

S: "Which is admirable. They've dropped off a service from the hospital which from my perspective is not so good mmmm"

D: "So the school teacher in the hospital would go out to the people in their homes now?"

S: "Yep That's the beginning of it. It hasn't started yet. They're in the process of working it through."

D: "and that's to get the school teacher out of the hospital?"

S: "No, its not so much about getting the school teacher out of the hospital, its about with the quick discharge from hospital, there's a period of time when a lot of patients are discharged from hospital and are at home. Where as, once upon a time, they would have done their recovery in hospital and the school teacher would have serviced them in hospital. Now that time is at home, and it can be as much as two to three weeks and that's. ."

D: "I've heard one of the problems with that is (that) people still give themselves permission to be sick because they are a lot sicker in the community than they used to be?"

S: "Yeah, and it is about, you know. Like some of the things that we have to be concerned about is that people are leaving hospital and they still haven't come through the trauma of the event of accidents and changes to their body imagery. So they will go home, and may get stuck in that sickness model, when in actual fact they can be facilitated back into school. But that's big changes for school as kids are coming back with plasters and hip spikers and pins and all that sort of thing"

D: "whereas they wouldn't have in the past?"

S: "Oh they would have stayed in hospital. Now they're discharged after two or three days with big pills and signs and things like that."

D: "Are they given enough? Would there be a place for them to be given something when they leave which they take away with them?"

S: "Were developing that.She's actually started a programme here. Her and I are actually working on that, of using photographic albums and putting together booklets that have got photographs to assist the kids re-entry into school. And its about giving them the language to understand what it is so that they can talk to their school mates. Or from time to time we'll go out and go into their school and do the education programme and say, I guess your wondering and you've got lots of questions about what happened here. This is how this happened. Cause its very difficult for a young person to stand up and do all of that, um, and I'd come in and do a half hour spiel. We'd talk about it. And like with the young people we'd say "what do you think of the questions that your friends are going *to ask? What have we got to answer here? They know the questions, most of the time they've got them pretty much on the head"*

D: "Its the first thing they'd think about"

S: "Yeah, you know, like how heavy is this? There's lots of questions. You know Susan will show you that stuff, its really interesting. And we've had some really good results because what's been happening is ,the kids would be going off to school for a day, two days, couldn't cope and go home and then get out of their peer grouping. So its very successful and its very supportive but its very time consuming. But when you take a photo album the cost is a lot. In fact the miseral frame is 5 thousand dollars and the kid goes home with it. So, you know, for maybe five ten dollars we can make a photographic book."

D: "So you'd do that for the individual kid?"

S: "Yep"

D: "or have you got some kind of..?"

S: "No, no we do it individually."

D: "That's really impressive."

S: "Yeah,it is. Its a lot of hard work."

D: "I can see that you have lots of videos up there."

S: "those are videos for the teenagers they're kept in here "

D: " and that's part of the service for this ward. Like if they're looking bored you can just...."

S: "Yep, loan out, they'll be loaned out overnight."

D: "Oh great."

S: "This is her when she came in."

D: "and you do all this here?"

S: " This is her photograph and then we photocopy it on here."

D: "Oh O.K.."

D: "and you have your own colour photocopier and stuff?"

S: "Yeah, yeah and this is how she drew her emiseral frame."

D: "And this is all individually written for her?"

S: "Yeah"

D: "that's great!"

S: "So this was her. This was her picture that she drew out of the thing here. These were her feelings"

D: "and they get to keep this as their own personal diary?"

S: "this is, there's, this is about working their feelings. This is her learning to clean their pin sites. So she's got these pins in her legs and you have to clean around them every day and you've got to turn these little nuts and bolts, its really complex."

D: "is it very painful?"

S: "Yep it can be. So you can see here, she is going through the process, things that were easy to do, things that were hard to do. So she's given us permission to share this book with other kids, and this is from her. These are the kids that I met at the hospital and these are her questions, "why have you got that frame on your leg?" 'Does it hurt?' Only the first time when I started to move it 'Does it hurt now?' no because I'm used to it now' Do you like having a frame?' No not really, but its helping my leg grow longer' 'How long is it on for?' 6-8 weeks"

D: "That's really fantastic"

S: "Its huge, its huge, aye? So sheand her mother said, "no, we can go back and do this ourselves without teachers" but some of the families who find it overwhelming um "

D: "but just for them to know that there is another person who'se been through it "

S: "They take this book. So this is her stay. So, if this was another kid we'd just put They're all quite different.

D: "But the fact that you can show these to the kids in here as well "

S: "You see, this is the sort of thing that they go home with, and they have to live with for 6-8 months."

D: "hard work."

S: "So April had a really really complex one and we did up her home care and her schooling programme- how many twists, how many turns. So that was the process, and that was the do it. We had a huge blow-up picture of it. So that, beside this, was a big picture and we'd marked all the pieces, so that she could do it. And the nurses had taught her and her mother."

D: "That's really fantastic."

S: "Yeah, it works great. But its a lot of work, yeah, yeah, but we're really proud of it."

D: "So you're actually creating resources."

S: "Yes, yeah, you do. She was a young girl, and she had menicochal meningitis when she was little. She was born perfect, beautiful at 18 months. She got menicochal meningitis. She's lost bits and pieces of her hands. She's got facial scaring. A lot of work has been done. she had her face lengthened. When she first came, she wouldn't come out of her room, and then she'd come down and she would only have it covered now. This was a young girl that we would have to re-enter into school and she was going to have to manage because it was going to be on for 8 months. You can't take children out and give them 8 months out of school and get way behind. So then we taught her. She'd come down to the playroom and take it off and we'd talk to her. So when she did that, as I told you, we blew this up on the photocopy machine and then she started coming up. We taught her the coping strategies for doing it- the skills to talk about it and understand it, the cost of it. She was very proud of the fact that it cost seven and a half thousand dollars. But still other kids "

D: "the apparatus?"

S: "Yep, just the apparatus. So we talked with the school and she could wear a long skirt and we got the physio to get her mobilised, walking, because the weight is huge. So she had to learn to be on crutches."

D: "so she can actually walk with that on?"

S: "Yeah, You see, she's completely independent. We were expecting her to come back to hospital on a regular basis, like every 3-4 weeks with infected pin sites. And she came back with one minor infection. And that's what we're finding with the kids. But that's a lot to go back to school with. Its a lot for the teachers to cope with in the schools as well. Plus they had to supervise her. She had to change pins there, there, there and there, every day. One had a quarter turn, one had a half turn, one had a full turn."

D: "So that's sort of to pull it? to straighten it?"

S: "Yeah. They broke her leg and what happens is, it makes them grow a little bit and then they move it again."

D: "It sounds like it would be very painful."

S: "Yeah it is. It has the potential to be. Were you in with braces and that?"

D: "No, no I wasn't."

S: "So that's part of, Its a huge team effort to do it. She went back to school. We re-entered her to school."

D: "I guess the fact that she only had one infection was a testament to how she actually managed that."

S: "and how well her family managed it, and her school managed it. So it was a team. The team here and the team out there. But that's what we're asking of young people, a young 13 year old and her family."

D: "and the end product is good?"

S: "Yeah, she's got it off now. Its great. So this was her story and from that we've done about five or six "

D: "You had this on the ward?"

S: "No, this was a poster session just to show other people because we have done a book for her. And she took a book home and we kept one. So these are the things that kids, young people might want to know so they can actually understand their environment."

D: "But something more generic like I could put together a generic body."

S: "pack"

D: "so that it had every part of the body. So that you could just pull out the heart if that happened to be the part that you were looking at."

S: "Yep. That's what people have to be able to do. But in terms of adolescents going into hospital that is what we need to do here. You know, you could do some of those things. Things that are easy to do, things that are hard to do but that you managed. Self esteem, so that people working in other centres may have some ideas. But you could do things like what's going on inside X-rays, How do X-rays work, how do blood tests work, that sort of thing. You might like to do . Yeah, so I think that that's what people need to do in hospitals is develop resources that people can actually use for complex type things. So that's what you should be gearing your information for, you know ask for *information about, that's geared at your level, ask for mebbe   photographs so you can see in advance what it is."*

D: "You mean create a demand"

S: "Yeah, I mean, you know, to say to young people   understand what's happening to your body, you have to manage, um, and ask them. You can use examples of what you've seen here. People should be doing that around, whether they have a photographic, like this is a photographic book this is generic, but photographs that will help."

D: "The main thing about that is (that) you can actually have the actual ward and specify it to the real people."

S: "So the challenge to go out, you could say, is to build those resources but in guiding young people through. Other young people have found that it helps to actually see physical pictures of it, maybe videos of those sorts of things. They definitely help. Young people need that. People from some cultures are much more pictorial in their processing than other cultures, and some people are, I mean, I can sit in a blank room and see pictures on the wall and know what the room looks like. And other people will look at it and see the dirty walls as they are. But when I paint a picture, I can sit in this room and put a framework in there and that's cause I'm pictorial. Other people may not be able to do that. So if you're saying in words I could paint a picture inside my head, and some people when you say words they just see words, they cant visually see what they're doing and so they are   "

D: "adolescents are supposed to be quite visual."

S: "and that's, yeah they are. But, you know, it helps when your under stress to have photographs of those sorts of things. So you know to be aiming at those sorts of things is really important."

2 play specialists

D: "Could you give me a rough idea about how many teenagers you see. Would it be a couple a week or a month?"

T1: "In a week, I might come across 2 or 3"

T2: "In a week I might come across 6-10"

D: "really?"

T1: "Yeah she has a lot higher average than I have got"

T2: "And usually I'd have some 15 and 16 year olds and some children, some young people that have been asked to come down from adult wards to here."

D: "is the turn around quite fast?"

T1: "The average stay in hospital is 2 nights. I find with most of the older children I deal with its anywhere between 6 hours to several weeks depending on the diagnosis. Like asthma can be quite a short stay, while rheumatic fever can be quite a long stay. So there are different types of relationships that you are trying to build in those 2 periods."

D: "O.K. I guess we could ***begin with the challenges****"*

T1: "I guess one of the challenges that I have all the time is because I'm not skilled in adolescence.

I am very skilled in early childhood. is that first initial relationship, like how do I broach the young people without being condescending. But being that much older, I'm not actually on their wave length either. That for me is quite a major concern. When they come in, they're quite stressed. You know, quite often they are the first time round, and its quite a tricky. Its a tricky thing. You want to give them their space, but you want to make sure that they're O.K.. And I've just been having a conversation with a thirteen year old. Now, this is her second day and she says I am sick of people asking me how I am. People don't realise that, I'll tell you if I'm not feeling yucky and when I need assistance. So its those, you know, how you check out there O.K. without "

D: "offending them?

T1: "Yeah, those sorts of things. That for me is my biggest challenge."

T2: "I have quite a lot of rapport with adolescents, whether its due to my personality or I'm not quite sure why, but, um, one thing I do face is assisting when they're in incredible pain. So we've just finished doing a course in visual innovation and imagery."

D: "Have you started to use it?"

T2: "I haven't used it yet, but I'm looking at other ways of assisting children other than the

D: "Don't you have a pain specialist?"

T2: "We do, we do, but we're looking at other avenues as well as that."

T1: "Apart from medication?"

T2: "yeah, apart from medication. Especially for someone who has a below the knee amputation and the pain person has come in and done everything possible. and just looking at different ways of assisting"

D: "So the pain team don't use alternative medicines?"

T2: "They use the psych team but its just thinking..."

T1: "They tend to use a more medical model and what we're trained to do is give the children back as much control"

D: "autonomy"

T1: "Yeah, and how much can you regulate yourself. Not regulate yourself, but what can you do to help your state, yeah and that's it. And like recognising where you're at. How much you can manage, and how much somebody else needs to manage for you. Knowing the difference. In fact giving back the kids their autonomy, then they can do an awful lot for themselves. And we're quite often just walk strait over the top of that as well. So not only do we have, are we looking at, the model of adolescence, its like, how do you get that out to other professionals who don't recognise adolescence as being something else apart from children who make a lot of noise. What do you do?"

D: "Is that one of the biggest things that single out adolescents from other groups?"

T1: "I think its their stage of development that makes them different. You know, they're risk takers at that age. They're experimental, they're trying to find themselves, they're using other peoples identity to work off. Like if you say to a young child 'your doing a really good job there', they'll *just accept that as a fait a complis. Where as adolescents want to question more than that, 'why did I do a good job?"*

D: "why are you saying that "

T1: "Yeah, are you being condescending? What is it about me that elicits that sort of conversation? So I think they need their own space."

T2: "And using their own voice as well, is another thing, is encouraging them not to be positive, oh still to be positive about themselves but also to like be able to question doctors medical about what is happening with their own body"

T1: "It takes a fair bit of courage to stand up to a doctor and ask good questions"

T2: "Just learning that its O.K. Hey its O.K. to ask some of those questions"

T1: "And what were talking about is not an empowerment thing, you know, because if your going to empower someone it implies that you've taken something away and were not, and you know this is status quo for the children, young people, its let us build upon the steps that you've got to take it to the next level, its not taking something away and trying to give it back to you and I find that that happens quite easily"

T2: "and I use the words 'other young people have done this' and it makes them feel like well O.K. if those people can do that then you know.."

T1: "Its a peer thing, peers are important at that stage of development, so if you use that then its a teaching tool for them and its not all this adult said it how do you gain that for yourself and I think that's it goes back to one of the hardest things I find with them is finding that level and just building upon what they know"

D: "just finding out what they understand"

T1: "understand, yeah you know without being, cause I sometimes think that I can be, not overpowering but not always respectful of their space either, and for me is a tricky one, I'm not that used to dealing with adolescents"

D: "Its very hard when you have to assess people so swiftly especially when in such a short period of time you've got to try to work out if they're understanding difficult concepts"

T1: "Yes and that's your perception, what do you understand, you know you can't ask that straight out cause that's too scary, its a doozey, I was just thinking"

D: "Were moving onto that, its a natural progression"

T1: "I don't have, I don't know about you, but I can only talk of me personally, I haven't found any tools ***any information, any concepts*** *that I feel comfortable picking up and walking away with and thinking about like for me its this whole grey area, there's nothing there, Suzanne does some really good work through pictures, and talking and stories and things like that, I don't have those skills, I think that's a good thing to talk about"*

T2: "often like if the children have gone and had surgery they tend to be really comfortable with pencils rubbers things like that, and I just ask them if they're interested in art and what they're interested in at school and just get those feelings what's comfortable with them and I tend to um, with some of the long stay, young people that we have, if its something that could be traumatic, *looking at a burn, looking at different ways of having photos and then you can actually "*

D: "Their stories, the book of the girl with the leg brace"

T2: "Yeah there is a lot, Yeah, yeah so I do a lot with young people as well and especially with young people who have had below the knee amputation to and also getting some, like for a young person with a below the knee amputation we had he stressed that he likes a lot of physical so we went to the physio and said hey he likes the gym, and they came in and took a couple of hours out of their time and gave him some space because that was what he was interested in, and he started picking up and taking control back in his life and things like that so I think that's really important"

D: "The kind of books you've been making, would it be possible, would it be useful to have some sort of, would it be possible or useful to have some sort of design thing which people could do their own thing within, like something that is designed already but with spaces to put their individual stories in to write their individual pages in"

T2: "I tell you I think were looking at something along those lines aren't we?"

T1: "Yeah, I think there's a. I wouldn't like to see a book developed because I think that"

T2: "everybody's individual"

T1: "yeah everybody's different but what I'd love to see is an information pack that says have you thought about these ideas to use in like so you could pick and choose and match those ideas with that particular child or that particular circumstance or that particular feeling and then so that you put it together in a book for that child so that its a very individual book"

D: "I mean something like a loose leaf folder only a bit more cunning where you could take and take away bits and pieces?"

T1: "It doesn't even have to [end tape] and if your working it through in a progression and you have to follow the book, but like she says, blood tests you might pick out an art activity you have seen about blood tests, you might pick out another activity that you've seen in that book that deals with pain levels and how you can manage that and then put that into that child's book, so you have a concept book that, like dealing with feelings you know um..."

T2: "also brainstorming, so um, you know so instead of having an external fixative, you know the children observe it, they find out exactly what its all about, what it looks like, shapes, everything um, everything to do with their dressing changes, it takes a while but you know they get the full understanding of what its all about, and if we do it like how they actually do it at school you know?"

D: "You have been developing resources, ***perhaps you could talk about the kinds of resources that you have*** *ranging through the concepts from feelings to pain to individual"*

T2: "She builds them but I don't know what, that's the thing, I don't realise how much work I've pulled together with the young people so um"

T1: "I think that's were it comes from too, like when your working with the child each child triggers something different that you know that child needs so that if you had some sort of information package that your thinking O.K. if I flip through this concept, like a pain concept and it says you can do this, or have you thought about doing this this this and this or introducing this this and this to the *child then it gives you in the back of your mind the concepts so you can think yeah, that's appropriate for that child but that one wasn't so lets pull this together to make this book or this resource for this child, and that's where I get stuck, I know the goal I want here, but I don't have the goal of how to put it together over here, you know my thinking patterns aren't that far advanced, yet, I can do that for a small child, because that is how I was trained, I do that naturally, but it takes me a long time to do what Suzanne does to bring together that folder for a child, for a young person"*

D: "But you have already got the ingredients, I mean have you already got...?"

T1: "No we don't, I don't have the ingredients to make that folder, I don't have that process up here whereas she does it naturally she doesn't know that she does it"

T2: "and everything's very very brand new"

T1: "you have a recipe, and you don't know you have a recipe because your working on instinct with those children"

T2: "Yeah, yeah, I just pick up naturally what there needs are and what their interests are, its just the way I've always worked with young people and with children"

T1: "I need the recipe to do it, you know it's the different ways that we work"

D: "What would be really neat is to take some of the stuff that you've done and make it available for more people"

T2: "Although some of the young people that we have now already know that things we are using now are teaching tools for our other families, so that was the decision"

D: "So it's just beginning to happen?"

T2: "yeah, yep it's just beginning to happen"

T1: "Like the thing is it takes her to develop them"

T2: "develop the relationship with the children "

T1: "to put them together, that's a lot of time, she's just starting to make the recipes"

T2: "But I only, I only work with the families that I know that are comfortable too because I know that instincts with the families that they've got to be able to manage that too"

T1: "I mean that's what leads onto the next one for me, I don't know what's out there to help support me to do that, a few articles through child life, and that's all, I'm not good on my developmental stages for adolescents, I mean that's a whole area in itself. I'm not into adolescent culture, I think that's part of it for me, that's a culture that I don't really understand and I don't really know where to go to find the information to start off with where as for you its ingrained, its in here"

T2: "Yeah, though I'm not very sure how. No I am very passionate about young people and especially when they come in, they need their privacy they need all those things and its different from other play work they need a different space, yeah"

*D: "**do you feel that there is a space for some sort of resource, for more targeted at adolescents than at children?**"*

T2: "Yes"

T1: "Oh, gosh yes!"

D: "O.K. that was a really positive reaction"

[laughter] T1: "you've got it there, I yeah"

D: "Could you equate it to what you've seen in other age groups in terms of what you imagine it could be? or ***could you imagine what it might be?****"*

T1: "Oh like I think, I think there's times there that when you've got the kids together its having the skills to facilitate the talking between the peer groups, there's that side to it, there's having the written information for the children to access when and where they need it overseas there are some amazing computer programmes floating around that children can access on their own diseases or diagnosis, and things like that, now we don't actually have access to those, so were starting right at the basic book technique and creating it through when we know that we don't have the modern technology that we know is available for kids to punch into like I've just seen in the states. I mean some of that needs to be vetted, I'd agree because we don't know what's appropriate and what's not, but through the internet over there I know there are chat clubs for teenagers as support groups if they're in isolation or if they have those one off diagnosis where you might have say 10 in a hundred thousand where no one else in your town has that sort of stuff, I mean yeah, those sorts of things, how do you get contacts, how do you talk to people like that? um what support groups are out there, not at a disease or a diagnosis but at adolescence to get together and talk about what it's like to have a chronic illness."

D: "So your looking at some point in the future getting some kind of computer access to patients?"

T1: "We would like to, I mean we would like to, that something I would like to see is an information source there for adolescence, like a library source, I saw one in a hospital overseas and it worked on a two fold system there was computers where they had access to disks with information on it the internet, e-mail and those sorts of things there was library books there was reading as well, you know not only about diagnosis about self image about chronic illness about pain and there was also a support person there so if they couldn't channel themselves in the right direction then they could go and get support from that person"

D: "That's sort of your role as play specialist isn't it? is channelling them in the right direction to the right resources"

T1: "Mmm, quite often were just physically feeding that into them, what I see in the things for adolescence, not only is there a play specialist or an adolescent specialist working alongside them, there is an information bank over there that they can go and do themselves, so they're not always relying on us to feed them what we think is appropriate, you know its very easy for you to gate keep and to make an unconscious decision about what's accessible for this child, what you think they need to know, whereas children might start of on one tangent and then get hooked into something else and not realise that they were interested in that, you know that particular thing about it, we all do it when we go to the library, start of with one thing in mind and then learn a whole lot of other stuff that works along side that particular one thing and if its always an adult feeding in information then you stop that wider knowledge base happening"

D: "I think one of the problems I faced is that the whole thing is so broad I mean "

T2: "I mean we've got young mums having babies, we've got.."

D: "Yeah road accidents are quite different from other things"

T2: "Yeah"

T1: "It is, it is different issues, so there needs to be that base of information there for that as well, its not just the diagnosis, its the whole human life living thing that goes with it"

T2: "You see for a young mum to be forced to go to school when she's just had a baby is not appropriate"

T1: "It's not what she's interested in"

T2: "She was in the playroom and she was making things for her baby that's what she wanted to do"

T1: "and she was creating at a 10 year old level, shed gone back to her safety zone, of what she could manage at that time "

D: "So in terms of what I can actually achieve"

[laughter] T1: "Oh, you want to achieve something [laughter]"

D: "I have some basic ideas of some of the basic issues that people say are problems if I put together something that I hoped would be entertaining for that age group and tried it out on a few teenage people to see if it was maybe right and maybe gave them a little information at the end about where they could go for more information"

T1: "I think that's the key, not only do we just say this is it, that you can start them looking for themselves, some of them will pick it up some of them won't it all depends on their needs"

D: "The thing is it doesn't matter if they don't"

T1: "no it doesn't you know they've been given that opportunity and that is often what I think we miss with them is giving them the opportunity and we might not do it like now"

T2: "Like later on we were looking at, not like getting a rap book done, but done through the artwork and just words that they can express, you know what I mean"

T1: "and whether they pick it up like 6 months or 10 years down the track it doesn't matter it doesn't matter its there if and when they feel they need it"

D: "is that something that they take away with them that explains what they've been through"

T1: "We don't keep it its theirs how can you have pride in something or believe in something if it doesn't become yours, if you always have to give it away"

D: "at one time what I thought at one time might be interesting is getting the patients to communicate with each other, especially when they're quite isolated, the older teenagers and I was thinking how you could do that, whether you could have a Captain Scott North Pole diary where people added to it when they came in, but as part of my questionnaire"

T2: "That's why we have the graffiti board"

D: "Does that work quite well?"

T1: "It does"

T2: "it works always"

T1: "Its never empty, as soon as she takes it down and change it and you can see that within an hour there's another couple of comments on it"

T2: "I just get them to put up their own graffiti board and put up their own art work and everything so that, and frequently they choose just exactly what they want to do"

D: "What happens to your graffiti boards once you've finished?"

T2: "I usually give them to her"

T1: "Because I don't work in ward 2 I often go and stand there and read them, you know and I find it really interesting"

T2: "You know if someone's fallen in love with a nurse, you know its all those things that are usually happening out in the community "

T1: "Its just accepting them for what they are at that particular time"

T2: "Its like we did a Christmas poster and you know they did their own art work, Santa on a sleigh with the reindeer, you know and "

D: "I saw some of those along the corridor"

T2: "and further along they did their own bombing and you know all that kind of stuff"

T2: "You know its just finding what they're interested in, and as soon as you get that"

T1: "I think that once you start showing that its acceptable, that there are places around here that they can be used then that's a different feeling than visiting strangers like being in a place where they actually belong"

T2: "We've got young people and sometimes they don't want to go home because they just really "

D: "Been really well cared for"

T2: "Yeah, but that's not what we want"

D: "I read about one teenager in hospital who had a little sign that he put on the outside of his curtain that said 'do not disturb' or 'knock before you enter' or some equivalent to that, would it be useful to have something like that as part of a package, something that they.."

T1: "What would be useful is lots of different sentences saying things like 'Please don't disturb me at the moment I'm asleep, Please, I'm not feeling up to visitors at the moment, if you list a page of those different things what your doing is giving them the ideas and then they take it away and create their own sign and I think.. "

D: "So you give them the implements to do it, like you could give them the board"

T1: "The cardboard and the felts, you know they're better at it than we are"

D: "Do you find that they can do it, that they are able to do it?"

T1: "Yep, yes, oh yeah, I mean sometimes I've just said to somebody that you need to put a sign up outside your door that says I'm sleeping please don't disturb me, or please knock before you come in, for young girls 13 14 who are trying to get dressed its very embarrassing. I've just made the suggestion, and I've come back an hour or two later and they've been down to the play room and *found themselves a piece of paper, some of them have just scribbled it, some of them have actually taken the time to make it into an artwork and you see them on the doors. Its actually giving them the words and the permission and say that's o.k. but its also giving them the appropriate words you know like Don't come in doesn't work, that's not a choice, or Please knock first, because you don't have a choice, if you need your medications now you need it now, this is survival but there are ways of getting around that you know and I think that that, though often because they are so stressed they come up with the negative words not the positive words, yeah its being able to flick through and think yeah I like that bit of that sentence and that bit of that sentence and that's what I'll create for my own"*

D: "What I'm interested in, I think the sort of expertise that you guys have got is great, but where its needed as well is in the older teenagers in the adult wards, and what I would like to do is to take some of these ideas and put them in something that they could give without the expert necessarily being there, if that's possible"

T1: "yep, I sometimes think that that's worth it because it starts them thinking"

D: "and then they can say as well I'd really like to talk to somebody, I'd really like to talk to a play therapist"

T1: "yeah, and that's what its all about its not taking away its giving them back, its giving them the ideas, how many of those kids upstairs know that they can say that?"

T2: "yeah because when were up in ward x that time that young patient, when he saw me going up and down with resources he just called out, I said there is something you can do about this and I encouraged him to write a letter to the department just to say that this is not a place for me"

T1: "and that's giving them back those ideas, not putting words in their mouths its giving them the concepts to get out there and do it so they're proactive for themselves, those kids are smart enough, and I guess that's what I want to see, its those concepts and those ideas that I can pick up and use, to say have you thought about this?"

D: "so I could structure it more like and activity book where you have a suggestion and a set of examples"

T1: "Mmmm yeah"

T2: "That's a good idea"

D: "and then the equipment to do it"

T1: "Yep I think that's a great idea you could, mostly they'll be able to find the equipment or get it brought in or"

T2: "Yep"

T1: "Yeah I think that that's a valuable tool to have that we could use"

T2: "and then they can choose what they"

T1: "and then they can choose because like you say it depends on how your feeling or what your priority is at that particular time which bit that you need to take out of this resource that you'll produce and those life skills you teach them that life skill now it goes back into the community that's another life skill that they've learnt, so hospitals not a negative, I learnt to be able to do this"

D: "to be able to ask the appropriate person the appropriate questions"

T1: "Yeah, you know yeah there is something in there, you think of how many kids would stick a sign on their bedroom door, or how do you say to the teacher politely that's not my way, that's a life skill that we learn that you take to your employer right through your life"

D: "Something like helping patients to ask doctors, what would you do to help somebody do that? do you have something that would help someone in that situation?"

T1: "I always tell them to write down what they don't know because when you start talking to an authority like that your so busy listening to what somebody says and your process that bit and you forget the next bit then of course you forget the questions that you've got and till you have those answers to those questions how could you build it up?"

D: "would it be useful to give them a formal space somewhere?"

T1: "What are the questions that you need to have answered, yep a big sheet of paper, what are the questions I need to ask today? or what are the words I don't understand"

T2: "like a young person having wires put in his fingers how and why"

T1: "Yeah I want that technical information it's just a piece of wire now excuse me is it a very fine wire or is it a number 8?"

D: "That's something I was wondering whether to actually say, you know that it might be an idea to ask for pictures because not always the medical profession go to the bother of"

T1: "or they could tell you show me one"

T2: "Yeah I think that's the visual they have to especially the young people who have tissue expanders in they need to see the visual"

T1: "or be asked if they would like to see the visual what's your learning style do you learn, do you learn by being told something, do you learn by looking at something, do you learn by watching TV you know what's the way that you learn best of all? so how do you tell the other people the professionals around here, how do you tell them how to teach you what's going on?"

T2: "and quite often what happens is if somebody is unsure about an external fix, I get the nurse to go back to the doctor could they explain with the x-ray so yeah"

T1: "Give me a piece of this to feel before I have to have it done"

D: "Obviously ideally the medical profession should be doing that for people anyway, but giving the people the tools to ask the questions in case something is missed out wouldn't be doing any harm?"

T1: "No that's teaching these children that they are valuable respected people of this community, you know not just the community out there but in this hospital culture, they too are valuable people and they are part of the team that looks after them, its not the doctors and nurses that look after them its that whole big continuum its their family what goes together to make it right for that particular person that's here"

D: "During play therapy do people? like in the hospital journals they had a space to write about themselves and who they were in the family and the community and that sort of thing, do you think its important for people to be able to do that?"

T1: "Yes"

D: "or for people to be given a space to do that, and how does it does it happen with you in your play area?"

T1: "I think I do that a lot with talking, who are your family who's in there what do you like to do and I think those if you want to exclude family in this experience its like what do you bring from home that reminds you of your family do you bring your photos do you bring your pictures do you bring your special games, have you brought your address book so that you can either phone your friends or write to your friends how do you keep in contact"

T2: "how do you keep in touch with your own school"

T1: "how are you going to keep those contacts going as well, how are you going to know what the cats doing, and that's important, you know those sorts of things who's the person whose going to be the contact for you? how are you going to find out those bits of information for yourself without having to wait for somebody to come to you when they might not even know the questions you want answered, how do you give that too them your brothers and sisters, they're important what time have they got to come and visit you the guys off the basket ball team, you know no one can tell you about a game better than the guys that were right in the middle of it"

T2: "Yeah, and quite often we have talked to the families about how important their relationships are to continue then quite often you'll get a lot of parents saying we've had football teams come in we've had people from the netball and come in and"

T1: "We had a warrior through here the other day you know that was important"

T2: "But even their own softball team, their own"

T1: "and we missed you because you always do this and"

D: "But you'd need management or people on the ward to be very supportive for that to"

T1: "If you were to do that how would you organise that who would you talk to about organising those sorts of things"

D: "I've been reading that sometimes its difficult for people to know who to ask and who's who especially with the doctors"

T1: "so that's something that they need to figure out they need to know who.."

T2: "who's top dog!"

T1: "and they need to be proactive"

D: "How do you help people with that on the wards here?"

T1: "Basically this afternoon, I was just thinking of a young girl that I was working with, she was 13, she was also developmentally delayed but she had to be treated like a 13 year old so there was no way like Julie this is Doctor Phil he is the doctor looking after you Phil this is Julie its an introduction you know and its like this doctor does this particular job this nurse is that."


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B
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