

Patient and Family Perceptions of Pre-Admission and Surgical Short Stay

Family, Carer and Patient Feedback on the Proposals for
the Re-design of Elective Surgical and Anaesthetic Services
at the Royal Hospital for Sick Children, Yorkhill

Community Engagement Team
NHS Greater Glasgow and Clyde
22nd May 2009



Executive Summary

Families, children and young people participated in a consultation on the proposals contained within the Surgical Short Stay Group report 'Redesign of elective surgical and anaesthetic services – the patient journey' (May 2008). They critically reviewed, assessed and commented on the proposals for the development of pre-admission services, day surgery and 23 hour admission.

After considering the impact of the changes in the patient journey relating to three factors in pre-admission – an extra visit to Yorkhill, the services provided at pre-admission and the potential for coming in closer to the operation/ procedure - they **strongly endorsed the proposal to develop pre-admission.**

They also made a **strong recommendation to proceed with the development of day surgery and 23 hour admissions.**

However, families wished to retain an element of flexibility in the provision of such services urging that excellent two-way communication and information be used to ensure that a blanket approach was not adopted and that individual needs and conditions were accommodated within these developments.

Families stressed the importance of surgery or an investigation under anaesthetic to the patient and their family. The value of enhanced planning, information and preparedness was repeatedly raised and felt to merit any potential inconvenience in terms of additional time, travel or attendance.

“Preparations and information is all important. Although a pre-admission visit is an extra, benefits in enabling family to plan and prepare outweigh any disadvantages”

1. Introduction

This report describes the feedback from patients and families on the proposals for the re-design of elective surgical and anaesthetic services developed by a multi-disciplinary service re-design team at the Royal Hospital for Sick Children (RHSC). It has been prepared in order to inform the further development of these proposals, their implementation within Surgical and Anaesthetic Services and to contribute a user perspective to the on-going discussions of the Surgical Short Stay Group.

The report presents the ideas, hopes and aspirations of children, young people and families for elective surgical and anaesthetic services, as gathered through a programme of community engagement. It will describe the process undertaken to gather this feedback before detailing user's views of the proposals for re-design.

2. The Community Engagement Programme

A community engagement programme was developed for the Surgical Short Stay Group in order to ensure that patients and their families were informed of the work of the group, engaged in developing proposals for change and given the opportunity to review and inform their plans. As the proposals for the development of elective surgical and anaesthetic services would represent a number of changes to the patient

journey this programme gave them the opportunity to know what was being discussed and to feel involved in decision-making. In order to ensure that a representative group of families, children and young people had an opportunity to be involved in and influence the proposals a wide ranging programme of community engagement was developed.

The programme commenced with an initial survey undertaken in the surgical wards of the RHSC in September 2006. In this, 40 families using children's surgical and anaesthetic services took part in semi-structured interviews to ascertain their views of a proposed Pre-Admission Clinic. Following this early endorsement of the broad idea of pre-admission more detailed work was done to describe the patient journey. Families, teenagers and children's participated in a multi-disciplinary meeting to chart the patient journey in October 2007. They made up nearly 30% of the total group, helping professionals to understand what was important to them and what it was like to be on the receiving end of hospital care.

As the plans progressed and a draft Integrated Care Pathway (ICP) was produced families and patients once again assisted staff. The participation of 8 patients and 7 families in the Surgical Short Stay Group pilot of the ICP in July 2008 provided an opportunity to review its practical application.

Throughout this programme families and patients had representation on the Surgical Short Stay Group and latterly, on one of its implementation sub-groups.

2.1 Consultation of the Proposals for the Re-Design of Elective Surgical and Anaesthetic Services

The most recent piece of work in the programme has been a wide ranging consultation with families, children and young people on the proposals contained in the Surgical Short Stay Group report 'Redesign of elective surgical and anaesthetic services – the patient journey' (May 2008). This consultation used a number of methods to engage with and gather feedback from children, young people and families. These were:

1. Semi-structured interviews – delivered in the wards of the RHSC - to provide an opportunity for a representative group of current users of children's surgical and anaesthetic services to comment on the proposals for a Pre-Admission Clinic, Day Surgery and 23 Hour Admission
2. A patient/family survey – delivered in the wards of the RHSC and by on-line links to a wider group of patients
3. The provision of an on-line survey on Pre-Admission, Day Surgery and 23 Hour Admission for use with teenagers and geographic communities
4. The distribution of survey forms by national charities and voluntary organisations with a membership whose interests included elective surgical and anaesthetic services
5. Focus groups held with families and carers in community settings to allow them to discuss and comment on the proposals
6. Play sessions with younger children to allow them to comment on Pre-Admission, Day Surgery and 23 Hour Admission

In order to ensure that the programme was equitable, free from bias and representative of the wide range of families and patients using the services at the Royal Hospital for Sick Children the following steps were taken:

- Surveys, interviews and meetings were conducted by the Community Engagement Team. As skilled researchers they were adept at engaging patients and families but as staff external to the RHSC, they were unbiased in their presentation of the issues
- On-line surveys and contacts within national voluntary organisations were utilised to ensure that representative feedback was received from those who would have longer distances to travel to the RHSC to attend appointments
- Interviews and surveys were conducted within the wards in the RHSC to ensure that current users were commenting on the proposals
- Surveys, on-line surveys, meetings, play sessions and role play were used to give a wide range of users with differing ages, abilities and literacy levels the opportunity to participate

2.2 Profile of Respondents

Through these methods the project met with, spoke to and heard from 122 parents/families, nearly 20 teenagers and 8 younger children. The respondents represented a wide range of groups and communities of interest.

Gender: 52% of patients represented were boys, while 48% were girls

Disability: 60% of respondents reported that they or their child (the patient) had a disability or additional needs

Ethnicity: 90% of respondents were white, 9% Asian, 2% Chinese and 2% described their ethnic group as Black.

Age: A range of age groups participated in the consultation

- 0 -4 years 27%
- 5 – 12 years 43%
- 13 – 16 years 20%
- Over 16 years 10%

Geography: Respondents represented the local, regional and national aspects of attendance at elective surgical and anaesthetic services

- 61% of respondents came from the Glasgow area
- 17% from Ayrshire
- 10% from Lanarkshire
- 4% from Paisley
- 2% each from Dundee, the Borders, Edinburgh and Aberdeen

In particular these methods were successful in ensuring the participation of potentially excluded groups such as those from minority ethnic communities, those with significant caring responsibilities and those with communication difficulties.

3. Findings

The findings from the initial survey of families using services at the RHSC, conducted in September 2006, demonstrated a high approval rating for existing pre-admission services and a strong desire to see such services developed. This consultation presented participants with some more detailed information on what changes were being proposed and what these could mean for patients and their families. It then asked them to assess the impact of these changes on their experience of elective surgical and anaesthetic services and to judge whether, in the light of the impact on them, they would or would not recommend the development of the proposals.

The first section of the consultation addressed the development of pre-admission.

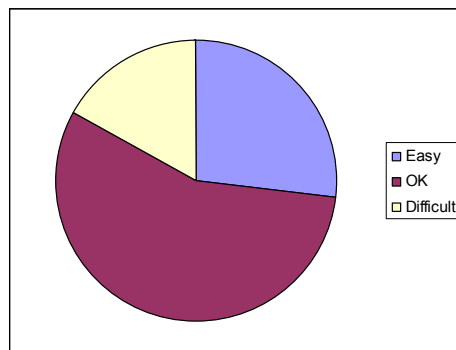
3.1 The Development of Pre-Admission Services

The changes to the patient journey associated with the development of pre-admission were outlined for patients and families. Three factors were described – an additional visit to attend a pre-admission clinic, the services offered by pre-admission and the potential for admission closer to the time of the surgery/investigation. Respondents were asked to assess the likely impact of these and to comment on any difficulties they could cause.

Respondents were first asked to judge the likely impact of an **extra visit to Yorkhill** for a pre-admission clinic. They reported that:

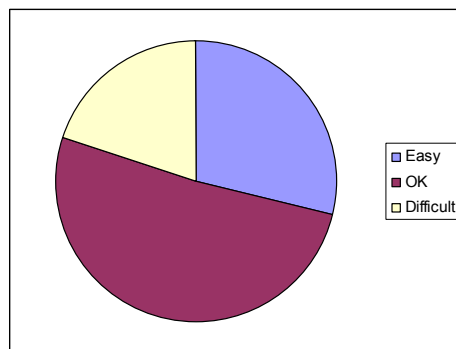
Getting time off work for an additional pre-admission appointment would be:

Easy	27%
OK	56%
Difficult	17%



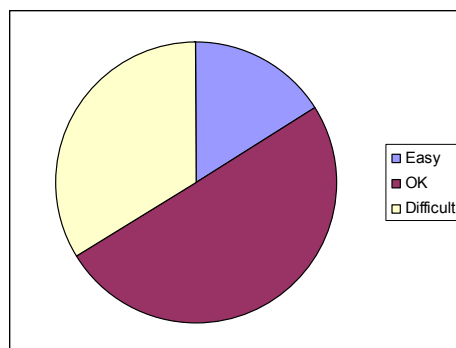
Fitting an additional pre-admission appointment in with other children and family commitments would be:

Easy	29%
OK	51%
Difficult	20%



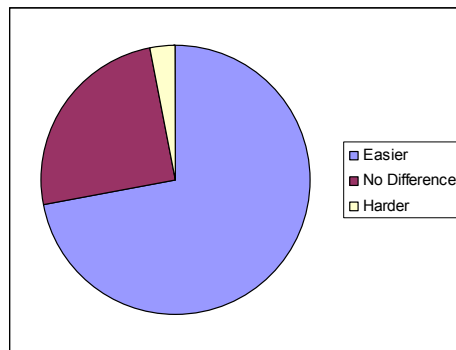
Making an additional journey to Yorkhill for a pre-admission appointment would be:

Easy	16%
OK	50%
Difficult	34%



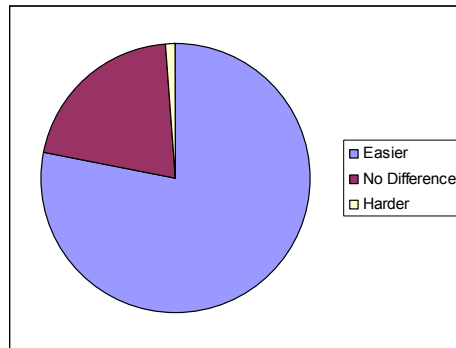
Organizing for the surgery or investigation and discharge would be:

Easier 72%
No difference 25%
Harder 3%



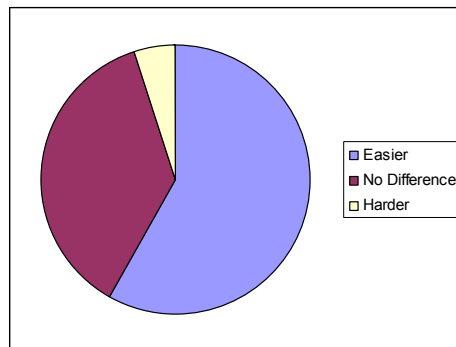
Supporting your child through surgery or an investigation would be:

Easier 78%
No difference 21%
Harder 1%



Managing your stress would be:

Easier 58%
No difference 37%
Harder 5%



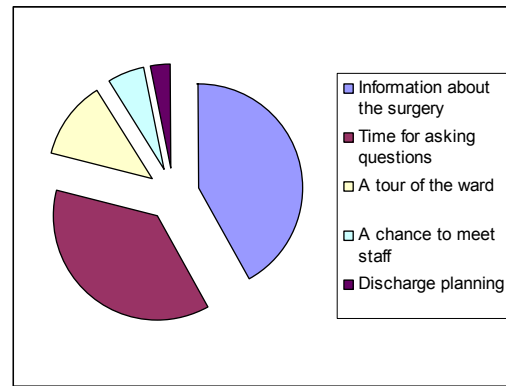
These findings show that there were some areas that may cause difficulties for families and patients – most notably in terms of getting time off to attend an additional appointment, fitting this in with other family commitments and with making a supplementary journey to the Yorkhill site. While the majority of respondents indicated that these issues would not cause a problem, it is still important to note that an additional appointment may create added inconvenience and stress for some patients and their families. In such cases it will be important to ensure that the extra appointment offers real benefits for patients and families.

“It is important that each journey to hospital has clear outcomes. Meeting for a chat is not a significant outcome when travelling from a rural area...”

The second factor examined was the **nature of the services available at pre-admission.**

Respondents were asked to reflect on the types of services typically offered at a pre-admission clinic and, apart from medical and nursing assessment which was a given, **to identify the service that they thought was the most important.**

Information about the surgery	42%
Time for asking questions	37%
A tour of the ward	12%
A chance to meet staff	6%
Discharge planning	3%



This finding demonstrates the importance to patients and families of information and the value they place on being knowledgeable and fully prepared for the upcoming surgery or investigation under anaesthetic. Families told us that:

“Parents and children can be very afraid of the consequences of coming into hospital for surgery. If someone could take the time to discuss what to expect then I feel this would cause less stress all round”

“Meeting the staff would be beneficial as it can be really daunting as our child has additional needs so we would like to pass on her requirements”

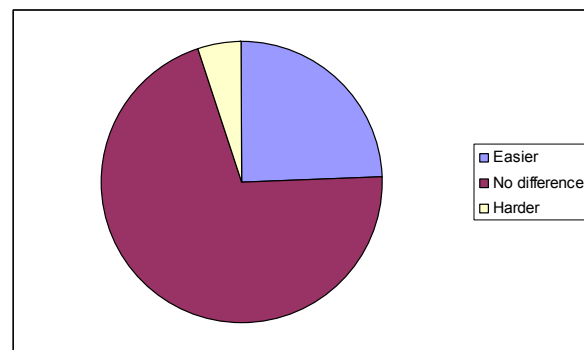
In play sessions, children also told us that they valued the chance to visit the hospital, to view the clinic areas and to meet with staff. This helped them prepare for their surgery/investigation and allayed many fears. The familiarity gained by showing them some of the buildings, facilities and staff they would meet when they came for their procedure appeared important in preparing them.

Respondents were then asked to reflect on the third factor in pre-admission – the potential for coming in to hospital on the day of the operation (rather than the day before) or the evening before (rather than early in the afternoon). It was noted that this would not be offered to all patients and that it would be dependent upon what they were having done.

They were asked if **coming into hospital nearer to the time of the operation/procedure** would make the following easier or harder to manage.

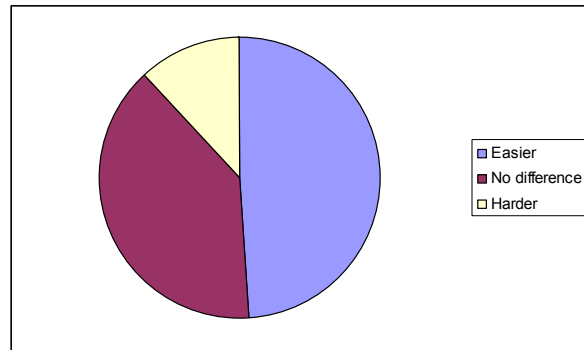
Getting time off work to attend the hospital

Easier	49%
No difference	41%
Harder	10%



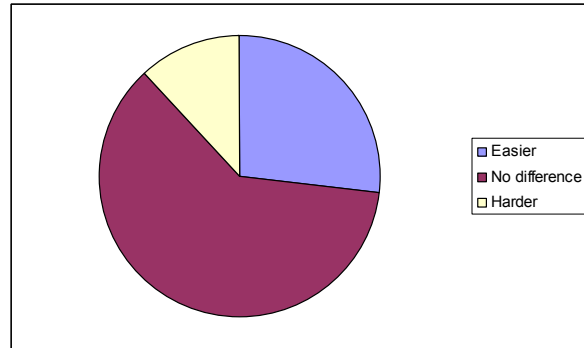
Fitting the surgery in with other children and family commitments

Easier 49%
No difference 39%
Harder 12%



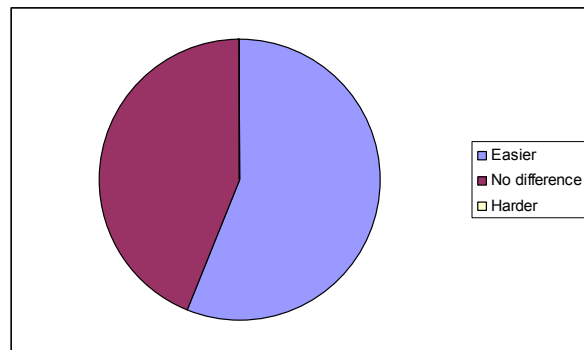
Travelling to and/or parking at Yorkhill

Easier 27%
No difference 61%
Harder 12%



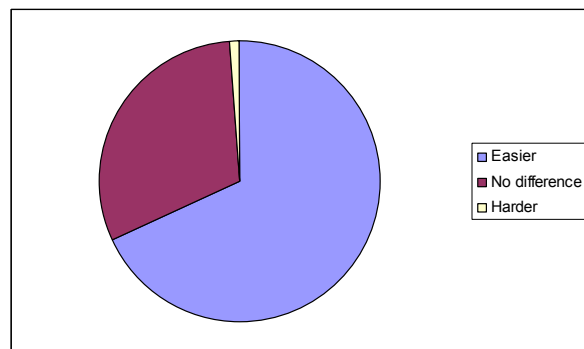
Organising what you need for the surgery and at discharge

Easier 56%
No difference 44%
Harder 0%



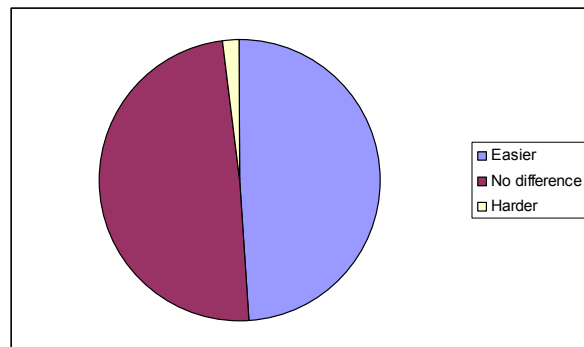
Supporting your child through their surgery

Easier 68%
No difference 31%
Harder 1%



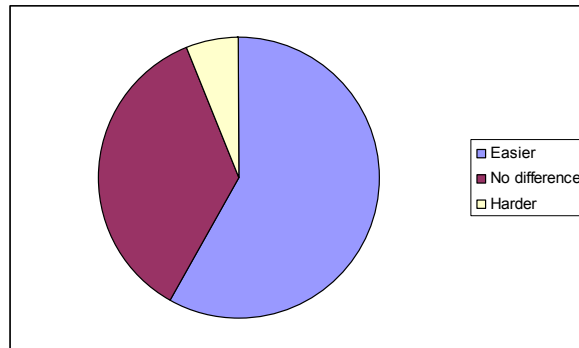
Managing at home after surgery

Easier 49%
No difference 49%
Harder 2%



Managing your stress

Easier	58%
No difference	36%
Harder	6%

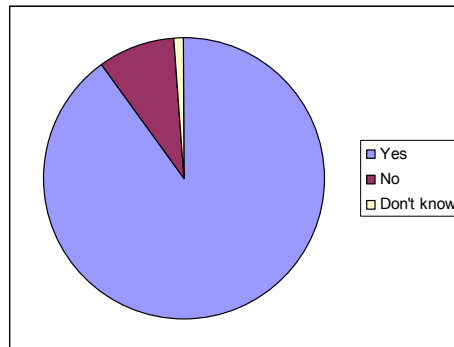


Thus, it can be seen that there were relatively few difficulties identified with the potential for coming into hospital closer to the time of an operation/ procedure. Feedback from the focus groups described a number of problems faced by some families because of other commitments, lack of transport options, single parent status, the complex needs of the patient or social factors that meant that any hospital stay – however long or short – would create difficulties and inconvenience. Respondents were keen to stress that there could be greater flexibility and support built into the patient journey, but that there would always be issues for some in balancing hospital procedures within family life.

Finally in this section, respondents were asked to consider the above three factors – the extra visit to Yorkhill, the services provided at pre-admission and the potential for coming in closer to the operation/ procedure - when deciding whether or not they would recommend the development of pre-admission services. Despite the difficulties this change in service delivery could present for some families there was a **strong endorsement of the proposal and an overwhelmingly positive recommendation to proceed to develop pre-admission.**

Taking the above into account, would you recommend the development of pre-admission services?

Yes	90%
No	9%
Don't know	1%



These findings are consistent with those of the 2006 survey in that families were overwhelmingly in favour of the development of pre-admission, although some felt that it would not be suitable for them or their child. The focus groups helped to clarify the nature of the difficulties in these developments with families outlining difficulties for their child in understanding the nature of, or information provided by pre-admission and so questioning its usefulness for them. There were few mentions made of long travel distances/times with some families feeling the additional journey would be inconvenient but worthy while others described this as a potential barrier. However, further analysis showed that the distance travelled to the Yorkhill site was not significant in the decision to recommend/not recommend pre-admission.

The feedback from the focus groups also provided insight into the high level of support for the development of this service with factors such as organizing for the surgery or investigation; preparing for discharge; supporting their child through the experience and managing stress identified as key to the decision to support the proposal. There was a strong consensus that the potential benefits in these areas would outweigh any increased inconvenience in terms of travel, managing family arrangements and securing additional time to attend a supplementary appointment.

“In terms of having an autistic child it would allow her to get used to the environment and for me to know where we would be going and what would be happening that’s probably less stressful although getting extra time away could be difficult”

Families took the view that surgery or an investigation under anaesthetic was a significant event in their family life – even if it was also a frequent experience – and as such the benefits in planning, information and preparedness offered by pre-admission were welcomed and felt to merit the additional time, travel and attendance that would be required.

“Preparations and information is all important. Although a pre-admission visit is an extra, benefits in enabling family to plan and prepare outweigh any disadvantages”

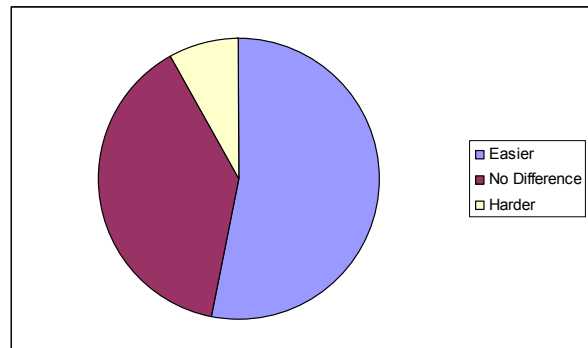
3.2 Day Surgery and 23 Hour Admission:

Respondents were then provided with information on the nature of day surgery and 23 hour stays and asked to consider how being invited for day surgery or a 23 hour admission would affect the patient journey and the impact of this on them and their family.

It was noted that day surgery and 23 hour admission would not be possible for all children or every condition, but respondents were asked to assess the likely impact of these and to comment on any difficulties that could arise. They reported that:

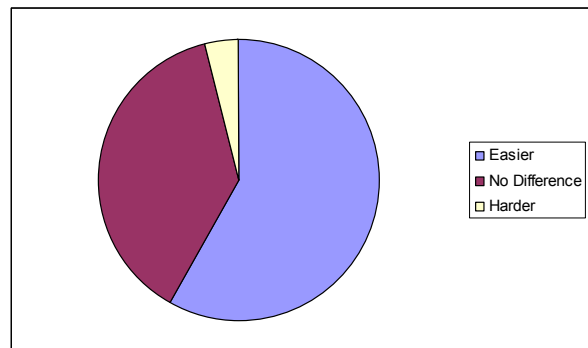
Getting time off work to attend the hospital

Easier	53%
No difference	39%
Harder	8%



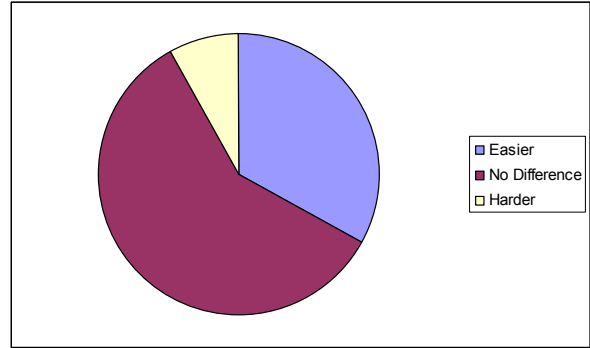
Fitting the surgery in with other children and family commitments

Easier	58%
No difference	38%
Harder	4%



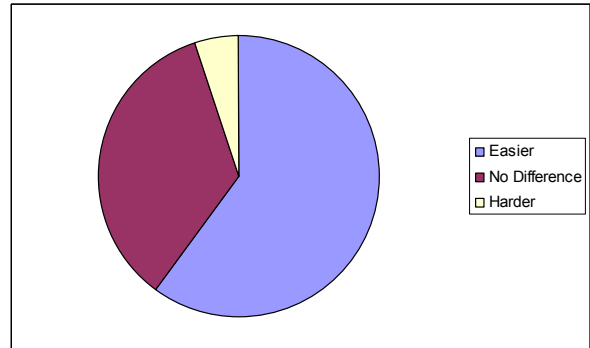
Travelling to and/or parking at Yorkhill

Easier 33%
No difference 59%
Harder 8%



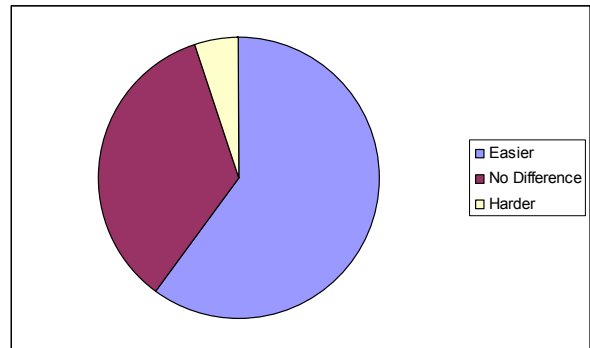
Organising what you need for the surgery and at discharge

Easier 60%
No difference 35%
Harder 5%



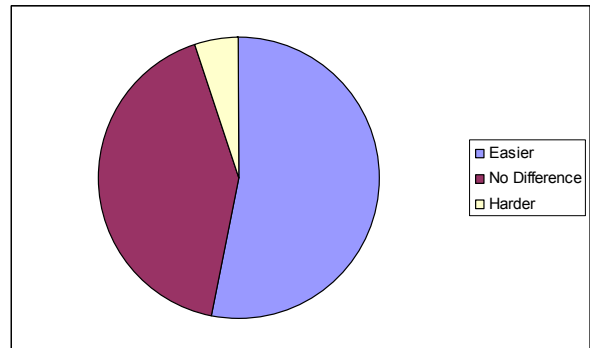
Supporting your child through their surgery

Easier 60%
No difference 35%
Harder 5%



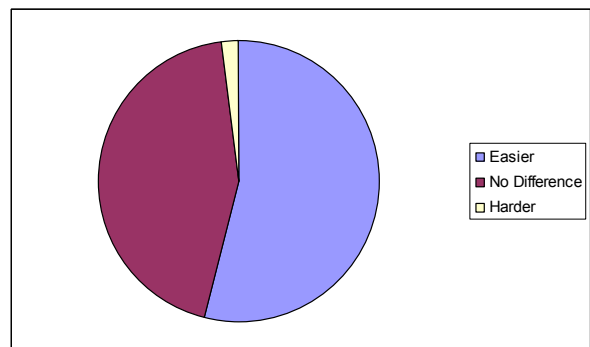
Managing at home after surgery

Easier 53%
No difference 42%
Harder 5%



Managing your stress

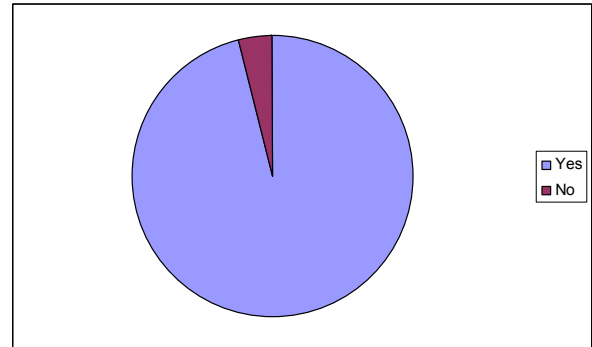
Easier 54%
No difference 44%
Harder 2%



Respondents were then asked to consider the above factors when deciding whether or not they would recommend the development of day surgery and 23 hour admissions. Once again there was **a strong endorsement of the proposal and an overwhelmingly positive recommendation to proceed.**

Overall, would you recommend the development of day and 23 hour admissions?

Yes 96%
No 4%



Discussions held within the focus groups once again provided insight into the high level of support for the development of this service with factors such as supporting their child through the experience and managing stress identified as key to the decision to support the proposal.

“Hospital stays can be frequent and stressful reducing 'non essential' time in wards would be wonderful”

“A lot of children with complex/ profound needs take badly to change. The quicker they are in and out of hospital, the better.”

“We care for our child 24-7 the quicker she gets home the better for her and us. She hates the hospital (and) would rather be at home”

However, there was some caution expressed in that families would not wish to see a ‘blanket’ approach applied, feeling that it would be important to ensure that factors such as the patient’s needs, co-morbidities, family and social factors such as travel were taken into account when deciding on whether day or 23 hour admission would be appropriate.

“As long as Doctors and Nurses pay attention to the patients journey i.e. plane, car, rail, ferries and the effect of the journey on the patient to avoid a blanket approach to the 23 hour turnaround”

“A short stay isn't always the best thing. My daughter values time to digest what is happening to her and to feel part of the hospital community. Shorter stays have seemed more of a shock to her.”

4. Conclusions

Families, children and young people participated in a consultation on the proposals contained within the Surgical Short Stay Group report ‘Redesign of elective surgical and anaesthetic services – the patient journey’ (May 2008). They critically reviewed, assessed and commented on the proposals for the development of pre-admission services, day surgery and 23 hour admission.

After considering the impact of the changes in the patient journey relating to three factors in pre-admission – an extra visit to Yorkhill, the services provided at pre-admission and the potential for coming in closer to the operation/ procedure - they **strongly endorsed the proposal to develop pre-admission.**

They also made a **strong recommendation to proceed with the development of day surgery and 23 hour admissions.**

However, families wished to retain an element of flexibility in the provision of such services urging that excellent two-way communication and information be used to ensure that a blanket approach was not adopted and that individual needs and conditions were accommodated within these developments.

“Keep processes individual. Not all families with the same condition have the same support needs. Important to find out what is most helpful in each circumstance. Need for excellent communication and information”

Despite the inconvenience to family life and the potential difficulties caused by attendance at the Yorkhill site, families stressed the importance of surgery or an investigation under anaesthetic to the patient and their family. The value of enhanced planning, information and preparedness was repeatedly raised and felt to merit any additional time, travel or attendance required.

“Preparations and information is all important. Although a pre-admission visit is an extra, benefits in enabling family to plan and prepare outweigh any disadvantages”

The Family and Youth Panels have reported that they have been pleased to play a role in the development of and consultation on these proposals. They particularly value the apparent influence that their feedback has had and hope that the views of the users of elective surgical and anaesthetic services can continue to make a contribution to these important services.

Kate Munro
Community Engagement Manager

22nd May 2009