

Health and Community Care: Patient Experience

Better Together: Scotland's Patient Experience Programme: Building on Children and Young People's Experience

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This report presents the findings from the 'Building on the Experiences of Children and Young People's component of Better Together Scotland's Patient Experience Programme. It explores aspects of health care that are most important to children and young people who use NHS services in Scotland. The purpose of this exploratory study with children and young people was to identify research topics and methodologies appropriate for further research as part of Better Together.

The study drew on the experiences of a range of children and young people, including those with long term conditions or impairments, those with experience as an in-patient and those who used primary care services. Five discussion groups were carried out between August and December 2008 with 25 children and young people (aged 6 to 16 years) across Scotland. This report presents the findings from this exploratory work.

Main Findings

- Children and young people wanted waiting areas to have age-appropriate activities and décor.
- There were mixed views about how easy it was for patients under 17 to ask questions in health care settings. There was little enthusiasm for health information on-line but text contact through mobile phones was more popular.
- There were both positive and negative views about some aspects of the hospital and other health care settings, such as cleanliness, food and furniture, but the children and young people talked about the disturbing effects of noise and smell. Privacy, but not isolation, was important.
- Good communication marked out good staff for these children and young people. Nurses were experienced as caring and friendly.
- The children and young people talked of fear about going to hospital or other health care settings. A wide range of things were experienced as scary from posters to treatments to seeing other ill patients.
- The children and young people had mixed views about whether they felt they were able to make decisions in health care settings.

Background

The *Better Together* programme, launched in February 2008, will collect detailed information on the experience of patients across NHS Scotland. These findings relate to exploratory work with children and young people.

Methodology

Child-centred research methods were utilised in this exploratory qualitative study with children and young people. Five focus groups took place between August and December 2008 with 25 children and young people (aged 6 to 16 years). Participants were recruited from different regions across Scotland. 12 of the 25 children and young people who took part were disabled with considerable experience of health services. Methods were adapted to suit the needs of all participants.

The focus group discussions used broad topic guides incorporating a range of activities aimed at stimulating talk, probing views and experiences, and maintaining the participants' interest and attention. These included: word showers; brainstorming what was 'good' and 'not so good' about health professionals and settings; a question lottery; and a 'pass the mic' activity with each participant recording a message for 'the person in charge of the NHS'.

Main Findings

The research identified **six domains of experience** relevant to children and young people.

Access and waiting

For most of the children and young people, making an appointment was not an issue. Car parking, however, was raised as a significant issue by a number of the participants. Children and young people often referred to 'the waiting room' in group discussions. Participants commonly felt that toys and activities provided in the waiting room were inappropriate for their age group. Almost all participants reported that there was little for them to do in the waiting room. It was felt there were toys for younger children and things to do for adults, but little for 'the people in the middle' (Girl, aged 8). A common complaint about the waiting room was that it was 'boring'. Décor was also reported as inappropriate for their age group but geared towards young children or described as colourless.

Better Information on health and healthcare

The participants had mixed views about whether they felt they got to ask questions in healthcare settings, with some feeling they did and others feeling they did not. Most of the young people said they felt they got to ask questions, although several reported they lacked the confidence or were too 'confused' or 'nervous' to do so.

Although most young people had access to the internet, none consulted health information online. Both children and young people expressed concerns about accessing health information online ('you can end up looking at the wrong thing and getting paranoid' Girl, 16). None of the young people asked were keen to access health information by e-mail or via social networking sites, although social networking sites were used by all of the young people. Concerns were raised about privacy and security. There was keen interest in receiving health information by text. Mobiles were seen as more private, with text messages easily deleted. Being able to ask their doctor questions and make and be reminded of appointments by text were popular suggestions.

Environmental needs in healthcare settings: comfortable and age-appropriate places to be

Participants described what was good and not so good about a variety of healthcare settings. The most detailed discussion in the groups focused on the hospital, particularly when the children or young people had recent or extensive experience of staying in hospital. There was also in-depth discussion in all groups of visiting the doctor's surgery.

The cleanliness of the hospital or other health care setting was commented on by only two participants, who felt the hospital 'could be cleaner'. Some of the children and young people made negative comments about the furniture in the hospital and doctor's surgery. One group of young people appreciated the furniture in their new local children's hospital ('it's got really groovy chairs...really comfortable' Girl, 15). The quality, healthiness and taste of food in hospital were also raised as an issue by several children and young people, although not a majority.

Many children and young people reported being disturbed by noise from other patients as well as staff in the hospital. The noise of 'crying babies' was reported as being particularly disturbing by both the children and young people ('I was always in the ward with all the babies and they were always awake...and all the nurses were always scrabbling about' Girl, 8).

Smell was the most commonly referred to sense as a way of describing the experience of going to hospital or visiting other healthcare settings. Children and young people reporting disliking the smell of: the beds, the doctor's surgery, doctors, the pharmacy, rubber gloves, bleach, the dentist, hospitals and older people.

Young people, in particular, raised the issue of privacy while in hospital. Although they sought to retain their privacy, none of the participants had a preference for single rooms. They wanted to be in a shared room with people their own age, with the facility for privacy when needed.

Building relationships and trusting professionals

Participants described what was good and not so good about the people they went to see about their health. Children and young people said positive things about doctors for different reasons. We identified four aspects to doctors being 'good' or the child/young person having a good relationship with their doctor. These were: the doctor as healer ('they can stop people being sick' Boy, 9); good communication and rapport with the doctor ('they're funny sometimes' Girl, 6); the doctor being friendly ('they're sometimes friendly, polite' Girl, 15); and the treats associated with the doctor ('they gave you a big box of things you could choose from' Girl, 8).

Children and young people had lots of positive things to say about nurses, who were commonly seen as more friendly and approachable than doctors. Participants particularly appreciated: the caring role of nurses; being allowed to call them by their first name; the physical and emotional comforts offered by the nurse ('kind words', 'a slice of toast') and the way they were less formal than doctors ('nurses say like sweetheart and stuff like that and doctors say just like your name' Girl, 8).

All of the young people asked had concerns about confidentiality when visiting their GP. Even when the GP had spoken to them about keeping things confidential, they still worried the doctor would tell other people about their visit.

Emotional impact of accessing healthcare

Children and young people spoke of what it felt like to go to hospital or visit the doctor. The most common feeling described by the participants was that of fear, and they talked about many things that made them scared, upset,

nervous or worried. The things cited as causing fear included: injections and treatment, surgery, when staff weren't friendly, frightening posters, having dentistry work done, seeing other ill patients, seeing siblings in hospital, and mum/dad leaving you alone in the hospital. Children and young people also had anticipatory fears of bad news. Commonly, participants worried about treatment – particularly in the hospital. 'Injections' or 'needles' were often spoken about when children or young people were talking about what they didn't like or what made them afraid. Going for an operation was also a cause of worry and fear, with anticipatory and retrospective fears of surgery described.

Involvement in decisions and control over choices

Children and young people had mixed views about whether they felt they got to make decisions in healthcare settings. Very few of the children and young people had developed ideas about decision making and control over choices in healthcare settings, although a small number of participants cited examples of good practice which seemed to have contributed positively to their experience of healthcare.

Methodological lessons learned

Lessons learned from this pilot work cover a number of different areas. In addition to recruiting through informal networks and community groups, participants could be recruited via NHS healthcare settings to ensure a high number of participants with recent patient experience. The children and young people enjoyed the range of research activities and games we offered to encourage talk about health care. However, those with more experience needed more time to talk and one on one interviews could be used in the future alongside group discussions. Those with extensive or recent patient experience were eager to relate their views. Young people were keen to talk about using new technologies. However, no-one was particularly interested in what they might like to see on the Better Together programme's website.

This exploratory research with children and young people identified health care issues relevant to them and useful methods which could be developed further to investigate more detailed aspects of health care important to children and young people who use NHS services in Scotland and involve them in service improvement.

This document, along with full research report of the project, and further information about social and policy research commissioned and published on behalf of the Scottish Government, can be viewed on the Internet at: <http://www.scotland.gov.uk/socialresearch>. If you have any further queries about social research, please contact us at socialresearch@scotland.gsi.gov.uk or on 0131-244 7560.



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