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Title: Evidence informed policy making for health communication

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Abstract

Background: Health care decision-making requires research evidence and good judgement. This applies to policy making, as much as it does to decisions about an individual's care. We have attempted to employ the principles of patient-involvement and evidence-based medicine to the development of policies for communication about newborn blood spot screening.

Methods: We identified points of communication along the newborn screening pathway and gathered evidence about these communication events. We asked three questions: what research evidence is available about screening and communication; what are parents' experiences of and preferences for communication about screening; and, to what extent does current parent information match the evidence, and meet parents needs? Drawing together these different forms of evidence, we employed consensus development methods, convening a multi-disciplined working group to guide our decisions in drafting communication resources and procedures. Finally we carried out a consultation to garner feedback on these draft communication policies.

Results: Feedback from our consultation was largely positive. We made changes to the format of the parent leaflet, and simplified the content. Where we faced contradictory advice, we followed NICE guidelines, prioritising the views of the majority of parents.

Discussion: We have employed a process of developing evidence-informed communication policy that incorporates a wide range of evidence, and incorporates the judgement of patients and health professionals, through the use of consensus development methods.

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Background

Decision-making in health care is facing two key challenges: the growing importance of evidence and an increased demand for patient involvement. The first of these, involves basing decisions on the best available research. Sackett makes the link between evidence-based decision-making and patient involvement, defining evidence-based medicine as: 'the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. It requires a bottom-up approach that integrates the best external evidence with individual clinical expertise and patient-choice' (1). Greenhalgh stresses the need for a broad definition of evidence in applying evidence-based medicine, calling for evidence not only about the effectiveness of a health intervention, but also information relevant to patients' lives: 'The call by Sackett and colleagues for an integration of research evidence with clinical expertise and clinical wisdom requires careful attention to the narrative and contextual aspects of illness experience' (2). Partnership with patients in applying evidence-based decision-making is needed for policy-level decisions as well as the clinical encounter (2-4).

Partnerships between the health service and patients in decision-making can involve different allocations of information, as well as different levels of responsibility for decisions (5). The paternalistic model assumes that the health professional has both the information and responsibility for decision-making on behalf of their patient (5). Shared decision-making involves patients and health professionals exchanging information, and sharing responsibility for the decision (5), whilst the informed choice model places the burden of information and the responsibility for the decision with patients (6). It is argued that there is no place for health professional recommendation in informed choice (7;8). Whilst all three models are seen in health care decision-making, there is a clear move away from paternalistic medicine, placing increased emphasis on evidence-based resources and policies supporting communication with patients (9).

Translating the principles of evidence-based medicine and patient involvement into collective decisions about policy requires consideration. Lessons can be drawn from clinical guideline development, that uses consensus development methods to combine evidence and judgement for policy (4). Clinical guideline methods require transparent and thorough methods for stakeholder involvement, including patients, carers and health professionals (10;11). A variety of 'involvement' methods are needed, allowing for both group discussion and more 'private' individual input (12). Everyone needs to know his or her contribution is valued (13), and need to be able to participate on an equal basis (12). This can be facilitated by circulating briefing papers to all contributors in advance of meetings to help ensure a shared level of understanding (12). With the involvement of stakeholders with differing priorities, there is an emphasis on

developing standards that might 'reasonably be suitable for the majority of patients' (10).

This paper describes how we have employed these consensus development methods in developing communication policy in the area of newborn blood spot screening.

Methods

Our aim was to employ the principles of evidence-based health, patient involvement and consensus development in a transparent way (see Figure 1).

Parent journey

We began by identifying the parent screening journey, from pregnancy when other screening may be offered, through newborn blood spot screening in the first week after birth, to the giving of screening results and referral for babies thought to be affected by each of the conditions. We gathered feedback from individual midwives to ensure the pathway was accurate.

The evidence-base

We sought to gather a broad range of evidence to inform our work (14). We focused on three questions:

- What are parents' experiences of communication along the newborn blood spot screening journey and what are their preferences?
- What research is available about communication and screening along the parent journey?
- How well does current parent information meet their needs?

Having obtained multi-centre research ethics committee approval, we carried out focus groups and interviews with 47 parents and 35 health professionals to find out their views and experiences of newborn blood spot screening.

We then adopted the approach recommended by the Centre for Health Information Quality of turning to rigorous, relevant sources of evidence (15) (ADD Booth-Clibborn ref 16 here). We systematically reviewed the research evidence, in the form of systematic reviews published on the Cochrane Library (16), and by the Health Technology Assessment Programme (17). This included reviewing evidence of: the effectiveness of

screening for the different conditions; the effectiveness of different ways of communicating with parents about screening; and parents' and health professionals' views about screening (18).

We drew on the DISCERN criteria for high quality patient information about treatment choices(19), and the National Screening Committee (NSC) criteria for policy-decisions about screening (20) to develop an appraisal tool for judging information about screening. This appraisal tool was used to systematically appraise existing parent and health professional information about newborn blood spot screening collected from throughout the UK and further afield (21).

Consensus development methods

We adopted formal consensus development methods for drafting our information and communication resources (12). The first step was to convene a mixed working group of parents with different experiences of screening, health professionals involved in delivering screening and key individuals involved in newborn screening policy at regional and national levels. Parents were offered additional support before, during and after the meetings, to help facilitate their involvement. We briefed group members with the evidence we had gathered about communication and screening and discussed this in relation to the parents' screening journey, using visual aids and group activity. Together we identified when information should be provided to parents in the screening pathway, by whom and in oral or written formats. Members of the group were given an opportunity to feedback on these communication guidelines individually, in private, as part of a consultation, described in more detail below.

Drawing on the DISCERN and NSC criteria we developed a draft leaflet template. This was included in background information sent to group members in advance of our first meeting. It was revised during the meeting through small group discussions, on the basis of which we drew up a 'consensus' version. Following our first meeting individuals were given an opportunity to provide feedback privately by post and email. On the basis of this feedback we drew up a working template for our parent leaflet.

In advance of our second meeting, we drafted initial wording for each item on this working template, drawing on our systematic review of existing parent information (21;22). This draft wording was sent out to all group members in background papers for this meeting. During the meeting, members of the group were given an opportunity to revise our draft wording through structured small group discussions. Again, following the meeting, a 'consensus' version of the wording was drawn together. As before, the

draft wording for the leaflet was sent to participants for feedback on an individual 'private' level, a process described in more detail below.

In order to check our interpretation of different people's input thus far, we sent the leaflet and the corresponding communication guidelines for consultation to all those who had contributed to their design: participants from our working group; parents and health professionals who took part in interviews and focus groups; and key individuals such as those involved in implementing other newborn screening programmes, who had advised us during the development process. We asked both closed and open-ended questions about the proposed timing, provider and format of information for parents, as well as the layout and content of the leaflet. Although the consultation was anonymous, we asked respondents to indicate their experience of newborn screening, for example as a parent of a child found to have one of the conditions, or a health professional counseling parents and so on. Responses were analysed and amendments made to the leaflet and guidelines (23).

Results

Feedback on the outputs of our consensus development process

Fifty-three percent of the consultation recipients responded (52/99), including 21 parents (16 parents with babies found to be affected by conditions following screening, and five parents with babies found to be unaffected), and 23 health professionals (7 of whom were midwives). A further eight respondents were involved in developing or managing different aspects of screening programmes. (see Figure 2).

We elicited feedback to 30 of our proposals using Likert scales, asking respondents to indicate their views on a spectrum between 'strongly agreed' and 'strongly disagreed'. The majority of respondents were supportive of all our proposals. The least popular was our proposal for developing a video for parents, which gained agreement from 45 per cent of respondents, with 12 per cent disagreeing and the remaining 43 per cent neither agreeing nor disagreeing. We asked a further 12 open-ended questions in order to elicit more detailed answers. Responses ranged from agreement to suggestions of amendments and more detailed critiques.

Whilst gaining support for most of our proposals enabled us to have confidence in the decisions we had taken, we also obtained contradictory feedback on some aspects of the leaflets. This presented a dilemma about how to move forward. This arose in relation to the level of detail within the leaflet. Support for detailed information about screening and the different conditions generally came either from health professionals with a particular interest in this area, or parents whose children had been affected by the conditions. Concern that the leaflet was too detailed, too long and too technical

generally came from midwives and parents of screened babies who were found to be unaffected by the conditions.

Our consultation also included clear advice from parents and health professionals to change the layout of the parent leaflet considerably. The leaflet was viewed as too wordy, without enough white space or pictures.

The products

Following the feedback from our consultation we produced communication guidelines for health professionals discussing newborn screening with parents, and an accompanying professionally-designed parent leaflet containing basic information. We reflect below on the process we went through in developing these products.

Discussion

Throughout the process of developing evidence-based communication policy in partnership with parents, we drew on a range of knowledge. Decisions about who should discuss newborn screening with parents, and when, and the leaflet template, were all based on the experience of parents and midwives, those with experience of affected newborns and those with experience of unaffected newborns, and specialists in newborn screening. The information content for both products was drawn from the research evidence of systematic reviews of screening and communication; this research evidence also informed the judgements of the working group throughout the process. The level of detail in the parent leaflet (i.e. brief) was informed by the experience and judgement of parents and midwives, those with experience of unaffected newborns being more influential than those with experience of affected newborns. This decision was supported by the balance of the population screened (the majority of parents experience newborn blood spot screening as a minor and routine part of neonatal care and 99.9 per cent receive 'normal' results, receiving no follow-up), and NICE guidelines (10). The textual style was informed by the craft of authors of previous leaflets, and the experience and judgment of parents and health professionals. The design of the leaflet was based on the experience and judgment of parents and health professionals, and the craft of graphic designers whilst the level of detail, textual style and the design of the communication guidelines were informed by health professionals.

In developing these resources we drew on three different types of knowledge, attempting to incorporate evidence from research; from parents' and health professionals' experience; and to learn from craft or practice knowledge reflected in existing information resources. We also sought to employ consensus development methods to make judgements in translating the evidence into policy. We therefore feel confident in saying we have employed transparent evidence-based consensus development methods in producing resources and policy to support decisions about

family health care. One decision did need to be made in the absence of consensus, regarding the level of detail in the parent leaflet, and we relied on NICE guidance to find a way forward (10).

The literature on communication policies is varied, focussing mainly on patient information. Some of the best known authorities on evidence-based information for patients provide checklists for judging resources, rather than recommending a process for their development (24;25). Others do describe steps in developing patient leaflets although guidance on the whole process is scant (26). The literature strongly advocates the involvement of stakeholders, and specifically patients (11;27). Reviewing existing information resources is also recommended, although we only identified one case in which existing resources were systematically reviewed using an appraisal tool especially designed for the purpose (28). Evidence-based patient information is strongly advocated (15;29), and supported directly in the National Screening Committee's second report (20). Others describe the process of prior consultation and piloting newly developed information resources (27;30). Practical advice on how to translate information needs and research evidence into communication policies is lacking. In contrast, consensus development methods are available for the development of clinical policy (10;12). Only the Royal College of Anaesthetists' report describes a similar transparent process for developing patient information that incorporates the evidence-base, stakeholder involvement, and consensus development (28;29).

Conclusion

Patient involvement in decision-making requires a judicious use of evidence by the patient and health professional together. Collective decisions, such as those needed for policy-development, raise the challenges of applying the collective judgements of all stakeholders to the evidence and reaching consensus (or not). By applying the principles of evidence-based health and consensus development, our methods provide a transparent route for collating evidence and exercising judgement to develop patient information and communication policy. In addition to research evidence, this required drawing on experiential knowledge of parents and health professionals, the craft or practice knowledge of health professionals and graphic designers and the research and facilitation skills of the parent support research team.

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publication are those of the authors and not necessarily those of the Department of Health.

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Figure 1: An overview of our methods

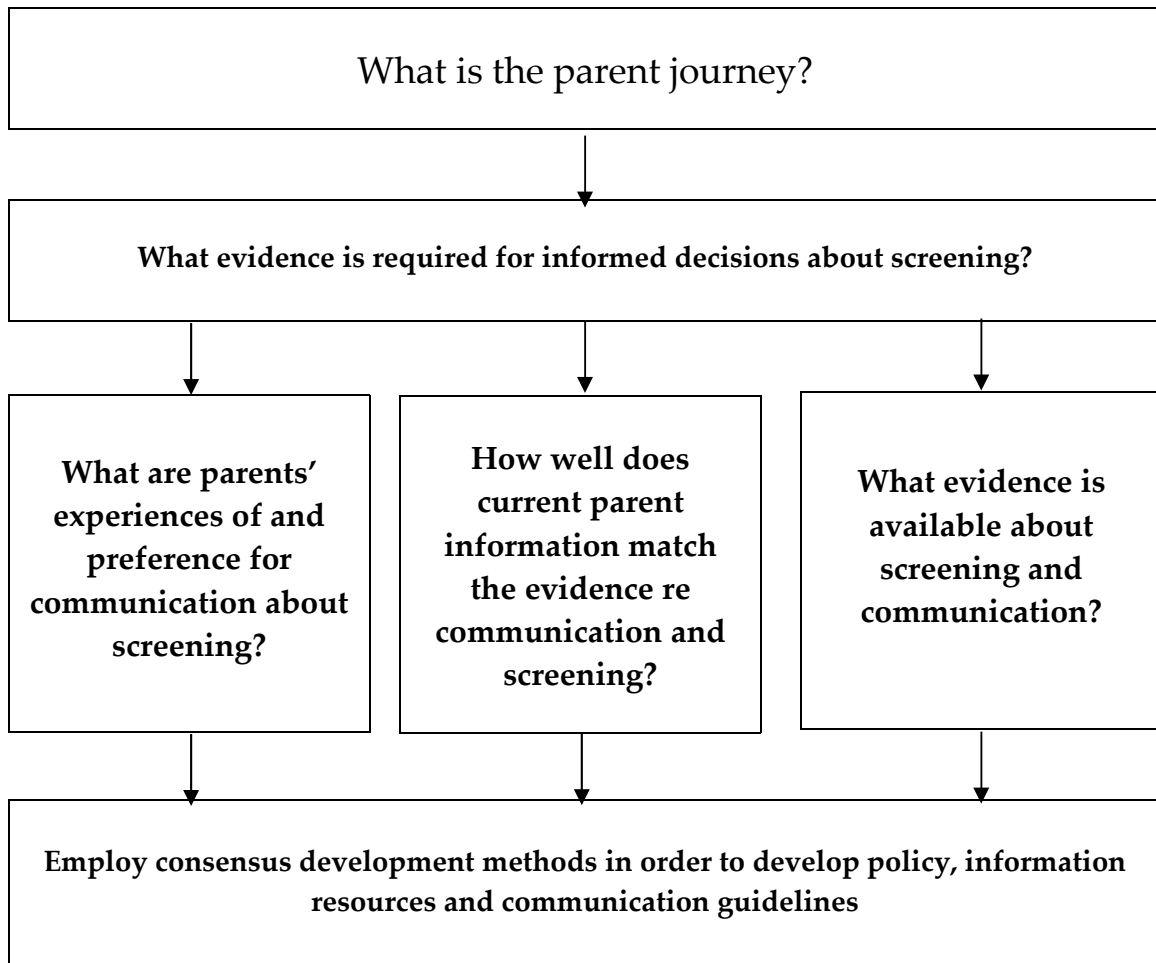


Figure 2: Consultation respondents

| Respondent | Frequency |
|--|------------------|
| Parents of a baby not affected by any of the screened conditions | 3 |
| Parents of a babies affected by one of the conditions | 16 |
| Parents of a baby who is a carrier of cystic fibrosis | 1 |
| Parent of a baby who had a blood sample taken on more than one occasion for blood spot screening | 1 |
| <i>Total number of parents</i> | 21 |
| Midwives | 7 |
| Health visitors | 2 |
| General practitioners | 2 |
| Counsellors / specialist nurses | 8 |
| Paediatricians | 3 |
| Lab directors | 1 |
| <i>Total number of health professionals</i> | 23 |
| Others involved in developing and delivering services for newborn screening | 8 |
| <i>Overall total</i> | 52 |