Public understanding of health and social care research

Research report
Executive summary

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Fiona McAllister, Managing Director, Beaufort Research
Adam Blunt, Associate Director, Beaufort Research

Views expressed in this report are those of the researcher and not necessarily those of the Welsh Government.

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For further information please contact:
Angela Martin
National Institute for Social Care and Health Research (NISCHR)
Welsh Government
029 2082 3686
Email: MartinA4@Wales.GSI.Gov.UK
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Introduction

Beaufort Research was commissioned to undertake research to help the Welsh Government develop an understanding of current public attitudes to and perceptions of health and social care (H&SC) research. This work will inform the development of a new initiative to raise awareness and understanding of the importance of health and social care research. The initiative is aimed at engaging the population of Wales with research, increasing public involvement and participation in research.

The research consisted of two stages: firstly, eight focus groups with a broad cross section of adults in Wales, with fieldwork between 18 September to 2 October 2014; followed by a second stage of quantitative research using Beaufort’s Wales Omnibus Survey, involving face-to-face interviews with a representative sample of 1,003 adults across Wales in November / December 2014.

KEY RESEARCH THEMES

Awareness and understanding of health and social care research

Overall, the term ‘health and social care research’ did not mean a great deal to participants in the research. They often struggled to suggest anything in relation to the phrase in the focus groups and almost half of Welsh adults interviewed in the survey were unable to define the term.

In the focus groups, ‘health’ sometimes suggested institutions such as the NHS, hospitals, clinics, pharmaceutical companies and scientists. For some, it also brought to mind health professionals such as GPs and nurses. ‘Social care’ added a more human dimension to associations with the phrase, for example ‘elderly’ people, children, fostering, disabled people, vulnerable
people and welfare. It also had an association with facilities like ‘homes’ and ‘care homes’.

The ‘research’ element when combined with the rest of the term sometimes gave the impression of cures or solutions, improving services, policy, and wellbeing associations like fitness and healthy eating.

Low levels of familiarity with H&SC research were evident in the survey, with fewer than three in ten Welsh adults saying they know anything about it and more (almost four in ten) saying they know nothing at all about the topic. Lack of knowledge was particularly marked among those aged 16-24. The survey results also indicate that personal involvement in H&SC research among the Welsh public is relatively low – 8% of those interviewed were either currently taking part in an H&SC research study or had previously done so, and another 16% said they know someone who has. Slightly higher engagement and involvement in H&SC research was evident among the middle classes (ABC1 socio economic groups) than those in the working classes (C2DE)\(^1\).

As focus group participants became more informed on the topic of health and social care during the discussions, there was a general consensus that H&SC research is an ‘essential’ and ‘vital’ activity which is required in order to save lives. This view was echoed in the survey, where over nine in ten adults interviewed perceived H&SC research to be important, with the great majority (61% overall) seeing it as ‘very important’. However, initially participants in the discussions tended to focus on outcomes and benefits rather than process and how people might become involved.

\(^1\) Standard social grade definitions derived from the National Readership Survey (NRS) are as follows: AB – higher and intermediate managerial, administrative or professional occupations; C1 – supervisory or clerical, and junior managerial, administrative or professional occupations; C2 – skilled manual workers; DE – semi-skilled and unskilled manual workers, state pensioners or widows (no other earner), casual or lowest grade workers
Taking part in H&SC research: motivations and barriers

When asked in the survey how willing or unwilling they would be to take part in H&SC research, opinion was divided – despite its high perceived importance, a significant proportion of those interviewed (42%) would not be willing to do so and another 10% were undecided. In contrast, nearly half of the Welsh adults interviewed (48%) said they would be willing to take part.

Four main motivations to take part in H&SC research emerged from the focus groups, when the discussion explored what might prompt people to become involved. The motivations were as follows, broadly in order of priority:

- The potential benefit to family members now and in the future, with regular references to children;
- Participating for one’s own benefit. Some pointed out that they would take part if they were ill and thought that it would benefit their illness. Taking part for additional health screening was not a front-of-mind consideration;
- Benefiting the wider public now and in the future; with a small number of exceptions, it was not as motivating as benefiting loved ones or future family generations;
- The potential to play a role in medical progress was important to some from a sense of ‘moral duty’; and future family members would therefore benefit as well.

When these motivations were quantified in the survey, the most powerful reason for being willing to take part in H&SC research was ‘helping people and society generally’ (endorsed by seven in ten of those who said they would be willing to do so), suggesting that altruistic motives are very important. Around four in ten of those willing to take part gave ‘personal experience of the illness or disease’ and ‘helping family and friends’ as reasons.

The H&SC research examples shown to participants in the groups that included common conditions or settings drew the most interest (e.g. quality of
life research and genetic research). This reaction connected H&SC research to something more relevant in these people's lives at an emotional level, whereas previously it had seemed more distant. Some reported a willingness to consider participation having heard about these examples. Population research was of interest to some because it did not sound very risky or inconvenient.

The focus group participants were virtually unanimous in identifying concerns about risk and side effects as their main barrier to participation in H&SC research. This finding indicates that, despite being exposed during the group to a broader range of what H&SC research can involve, participants tended to revert to associations with clinical trials. This fear of risk was based on a mix of general perception, media story recollections, families’ or friends’ experiences, and word of mouth.

No other barrier was voiced strongly across the groups. Sometimes participants felt that it might be too time-consuming to take part and that an apparent lack of communication on H&SC research was part of the problem. Confidentiality concerns, other ethical issues and preferring not to find out about a potentially serious illness (e.g. an increased likelihood of developing cancer) were further, infrequent barriers mentioned.

In the survey, when those unwilling to take part in H&SC research were asked which of a list of reasons for not wanting to do so applied to them, the main barriers were two-fold: firstly, the time / effort perceived to be involved and, secondly, the possible risk to health (both selected by around one in three of this group). One in four cited ‘lack of information / understanding of what is involved’ and around one in eight said ‘concern about privacy / data confidentiality’ was a reason. Other barriers mentioned spontaneously by smaller proportions of this group were age (and a perception they were too old to participate – especially amongst the 65+ age group), health reasons and a lack of time.
When asked, focus group participants in general felt that anyone should be given the opportunity to take part, and expected that a broad and inclusive range of people would be necessary for research. However, some initially thought that ‘people with time on their hands’ and patients would be most likely to participate. Findings from the survey confirm the view that ‘everybody should be offered the opportunity to take part in H&SC research’ – over seven in ten Welsh adults were of this opinion, compared to just 5% disagreeing.

Understanding of the research cycle

Focus group participants tended to maintain that involvement opportunities were at the implementation stage. It was not clear to them where else the public could play a part in the research cycle without expertise, other than perhaps by fund-raising or donating to charity, if this action constituted part of the cycle.

Once they were more informed on the subject, some envisaged the public potentially playing a role at the idea or planning stage and also at the evaluation / recommendation stage.

Encouraging involvement and participation in H&SC research

A prominent idea from focus group participants was the use of face-to-face interactions, with preferences for discussions during which questions could be asked. GPs and health professionals were suggested as a trustworthy channel for encouraging people to take part. A second important influence for people (face-to-face) was to be able to hear from previous research participants, or their families if appropriate.

According to some, community groups, schools (e.g. reaching parents or, in the longer term, via the curriculum) and other local settings where people routinely spent their time would be effective channels for reaching them with communications on H&SC research.
Social media was widely considered to be a likely effective channel to reach people. Participants in the focus groups often suggested an ice bucket challenge type of initiative with the potential to go viral. Some felt social media might also help with longer term engagement. Celebrity involvement in the campaign was a further regular idea put forward by participants.

In addition, more traditional channels were suggested by group participants such as TV and radio ads, and printed media in community or health settings. In terms of key messages to include within a campaign, focus group participants' ideas tended to focus on the key motivation of the family and future generations - the benefit to the individual and his / her family in order to create a personal connection.

Six possible brand names were shown to participants in the focus groups but these were of limited appeal. Negative reactions centred on a lack of impact and vagueness over the meaning of the name. Participants, however, recognised the challenge in creating a brand name for this subject.

Together for Research tended to be the more popular, followed by People’s Research Wales. The inclusion of ‘Together’ and ‘People’s’ echoed participants' views that the brand name should focus on human elements rather than simply process. In addition, ‘Wales’ was thought by some to enhance the appeal of the name.

Conclusions and recommendations

Levels of involvement or engagement with H&SC research across Wales currently are limited. With a few exceptions, participants in the qualitative study reported not encountering regular communications or invitations to find out about, or participate in, H&SC research and fewer than one in ten Welsh adults surveyed had any direct personal experience of health and social care studies.
H&SC research and its outcomes, therefore, are not familiar or well understood. Focus group participants who did have relevant experience - either directly or through a family member - tended not to think of the experience when presented with the term H&SC research. Current communication is therefore a significant issue.

This point poses a particular challenge because of the limited familiarity and also because participation in health research (once discussed further) was often synonymous with clinical trials. Trials in turn carried strong risk associations in participants’ minds.

However, interest in the subject grows and connections are made when people are placed at the heart of H&SC research stories. References to common illnesses result in stronger connections, which immediately make the subject relevant to many, at an emotional level.

Even so, participants in this research were more likely to be receptive to H&SC research which appeared straightforward, involved little effort and no risk. Research that involved any element of risk would be evaluated against the potential positive impact on family members affected by the subject under research; or the impact on the individual taking part if that person also suffered from the condition.

Lower social grade (C2DE) audiences pose more of a challenge in terms of engagement with H&SC research than the upper (ABC1) social grades – not only are they less likely to have personal experience of H&SC research but they are also less likely to feel they know anything about it, less likely to recognise its value and are less likely to perceive it as very important. Therefore, more would be unwilling to take part than are willing, if asked. Older people (particularly the over 65s) are also less willing to participate than other groups because of a perception that their age is a barrier.
Recommendations

To encourage willingness to consider volunteering in principle and then taking that step to becoming involved and participating, a number of actions need to be considered:

- Develop coherent branding to help raise awareness, promote understanding and encourage participation (especially amongst young people, older people and those in the C2DE social grades);
- Ensure the branding tunes in to key motivators: people, outcomes, and future generations;
- Develop a strapline for the brand and a suite of positioning statements which can be used with different audiences or in different environments to make the brand work. This research confirms the complexity involved in creating a brand name that alone encompasses the key elements of H&SC research and resonates with the general public;
- Explore using Together for Research (Wales), or potentially Health Research Wales, with a strapline that refers to the benefits of H&SC research at a personal level (for example along the lines of ‘Get involved for your family and future generations’). Including the word ‘health’ helps participants begin to understand the initiative at a top level although lacks the human element associated with social care. Wellbeing Wales, a suggestion from the research, conveys more about the initiative in a succinct way, but may risk being associated with lifestyle type activities such as Health Challenge Wales;
- Launch a widespread communication campaign focusing on the key motivators;
- Ensure communications find participants by seeking to adopt changes to their current routine environments, for example in health settings with continued proactive approaches by health professionals with supporting literature; and in other community settings, for example via schools and education, charity events, the workplace and other environments in daily routines;
- Build social media into the campaign for example with a Facebook page raising awareness of H&SC research, with examples of people-focused outcomes;
- Ensure communications broaden and challenge people’s perceptions of H&SC research: for example it is not only about clinical trials; confidentiality is assured; it does not necessarily have to be too time-consuming; and there is more to research than simply the implementation stage in terms of public involvement;
- Include previous research participants in communications, whether in a face-to-face role (e.g. speaking in routine environments) or online / in printed media;
- Reassure potential participants that they will be informed of the outcomes of research, and the difference it will make to the lives of others. This activity can result in a rewarding feeling that they have helped. Online provides a relatively inexpensive means of keeping in touch with participants and also giving feedback;
- Explore what can be learned from blood and organ donation efforts to encourage participation; this could involve, over time, seeking to make participation in H&SC research socially desirable in line with giving blood and being on the Organ Donor Register;
- Explore the feasibility of targeting those who are on the Organ Donor Register or who give blood. This audience may be more likely to be warm to the idea of taking part in H&SC research;
- Explore opportunities to work in partnership with others to raise the profile of H&SC research, for example with charities / the third sector with a public facing presence such as shops on high streets. These sites could carry literature and display posters to raise visibility of the campaign among certain parts of the overall target audience;
- Evaluate campaign effectiveness with tracking research so that its impact can be robustly measured.