Engaging for increased research participation

Key findings and recommendations

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1. Introduction

In March 2014 University Hospital Southampton NHS Foundation Trust (UHS), with match-funding from NIHR Clinical Research Network: Wessex (NIHR CRN:Wessex), commissioned Alterline Research Ltd. to conduct a programme of market research to develop the evidence base for effective communications and engagement aimed at increasing patient and public participation in clinical research. This work sought to better understand the perceptions of and motivations and barriers to participation in clinical research across the Wessex region.

Alterline conducted 1101 telephone interviews with adults in Dorset, South Wiltshire, Hampshire and Isle of Wight (representative of the population by key demographics such as gender, age and location), 30 in-depth follow-up interviews and carried out interviews of 26 clinicians including hospital trust consultants, nurses, and GPs.

This report looks at the principal findings of the research and gives recommendations for increasing clinical research activity in the NHS through effective communications and engagement.

2. Key findings: the Public view

2.1 Clinical research is important

- 90% of people think that it is important for the NHS to support research into new treatments
- 47% of people said that they would be likely to take part in clinical research
- Clinical trial participation was discussed in only 5% of medical consultations in the previous 12 months, whilst only 15% of respondents had been asked about trial participation by a clinician at any point in their life
- Only 10% of those interviewed have ever taken part.

2.2 Characteristics of those most likely to participate

- Having previously participated (64%) or knowing someone who has (63%)
- Having a good understanding of clinical research (63%)
- Students (58%) and those unable to work (63%)
- Having a degree or equivalent level of education (58%)
- Registered organ donors (58%)
- People in very good health (57%)
- People who do regular volunteer work (55%)
- People who have given blood (54%)
- People aged 35-64 (52%).

2.3 Motivations for taking part

The top three motivations for taking part in clinical research were:

- Supporting research into a condition a close family member suffers from
- A positive impact on their own health
- Getting access to the latest treatment for a condition they have.

Altruistic motivations were also cited, including helping others by finding new treatments.

2.4 Barriers to taking part

- Concern about the risks is the main barrier to participation
- After risk not having the time, or needing to take time off work are important barriers
- In-depth interviews confirmed strong trust in clinicians to provide accurate information, and increased likelihood of participation through such discussions.

2.5 Positive experiences of clinical research

- 80% of people who have taken part in clinical research would recommend taking part to a friend or family member
- 44% of people who know someone who has taken part in clinical research said that they are more likely to participate now because of their experience.

2.6 Lacking knowledge and information

- 39% reported that they have very little understanding of clinical research
- Only 9% felt they had a very good understanding of clinical research
- Just 13% of respondents had actively sought information.

Information about side-effects and risk was rated most important, followed by knowing more about the process, the potential benefit of the drug or treatment and the time commitment involved.

3. Key findings: Healthcare professionals' views

3.1 Clinical research is vital, delivered by the minority

Healthcare professionals see clinical research as both necessary and vital for progressing medicine, however there was consensus that they and their peers split into two groups – a minority who are viewed as 'researchers', and those who are 'practitioners', focussed on clinical practice and delivery.

3.2 Motivations for getting involved in clinical research

Clinicians reported many reasons for getting involved in research, including:

- To advance the field
- Benefits to the wider patient group
- Benefit to specific patients
- Financial remuneration
- Bringing income into the organisation
- An interest in research
- Career development and publishing papers.

3.3 Barriers to getting involved in clinical research

Clinicians perceived key barriers to direct involvement in research:

- Time constraints
- Bureaucracy
- Difficulties with ethics and funding
- Lack of support
- Lack of awareness and opportunity
- Lack of interest
- Desire to give care rather than research.

3.4 Research opportunities

Respondents said they were being approached by a wide variety of sources, including internal members of staff, private companies and research networks.

3.5 Speaking to patients

- Those who are speaking to patients about clinical research do so because of an involvement in a project or because a patient has asked.
- Those who are not speaking to patients report a lack of time, lack of involvement and knowledge, that it is not on their patient's agenda or that they aren't being asked by patients.

3.6 Availability of information

- Most of those interviewed would feel confident speaking to patients about clinical research within their area of interest and expertise, or their department.
- When looking for information about clinical research, clinicians would turn to the internet, colleagues, and the research team.

4. Summary of findings and recommendations

4.1 People are positive about research and participation

The Wessex population views research in the NHS positively and a large proportion are open to participating: 90% of respondents think that it is important for the NHS to support research into new treatments, whilst 47% think it likely they would be willing to participate in clinical trials in the future.

Those that have participated have positive perceptions, and they will likely have a significant influence on others' future participation: 80% of people who have taken part in clinical research would recommend taking part to a friend or family member, whilst around half (44%) of people who know someone who has taken part in clinical research said that they are more likely to participate now because of their experience.

4.2 The critical conversations are not happening

The key finding that 95% of clinical interactions do not feature discussion of trial treatment options with a clearly willing public is critical to increasing research participation. Our study has confirmed the inherent trust placed in NHS clinicians to deliver clinical trial information and suggests that interventions focussed on clinical consultations could dramatically increase trial recruitment.

4.2.1 Recommendation 1

Communications supporting participation in interventional trials should be focussed on enabling effective clinical conversations, with a reduced emphasis on broad public awareness approaches.

4.3 Healthcare professionals perceive major barriers to involvement

The healthcare professionals interviewed were broadly positive about research; however they cite workload, time and lack of local trial information as constraints on discussion of research with patients. Better trial information was also identified as something that would increase the likelihood of discussing trial options with patients.

Clinicians self-segregate themselves into 'researchers' (an academically orientated minority) and 'practitioners', with the latter positive about the benefits of clinical research and open to research referrals/facilitation but unlikely to have direct involvement in, or lead their own, research.

Direct involvement in research by clinicians is limited by lack of programmed/sanctioned time within work plans, perceptions of excessive bureaucracy and perceived lack of support.

4.3.1 Recommendation 2

Local Clinical Research Networks, local research infrastructure and Trusts' senior leadership should support NHS clinicians' engagement with local clinical trials, and to explore management and education interventions to make communication with patients about trials a routine part of all NHS consultations. Specifically:

- Investment in integration of valid trial information online and/or in clinical software, for reference and referral during consultations.
- Active engagement of healthcare professionals inclined to perform research to develop their capacity and opportunity to do so, alongside engagement with those not inclined towards research themselves to support them in referring patients onto trials.
- Prospective development of healthcare professionals' attitude, capacity and responsibility re. research through appointment processes and contracts, work planning and CPD.
- Raising visibility and accessibility of R&D support infrastructure, and refocusing R&D support on end-to-end project management of research governance and administration for research active and research-inclined individuals.

4.4 The public need information, of immediate relevance to their health

Communications that have immediate health relevance and address concerns over risk and time commitments are likely to be most effective. The public's motivation for participation centred on potential benefits to one's own health or that of close friends and family, whilst perceived risk of harm and receiving the 'unknown' alongside concerns over time commitments and time off work were the biggest barriers to participation.

Better understanding of clinical research modifies perceptions of risk but only a minority have this understanding. Only 9% of respondents reported that they felt they understood clinical research very well, with this group the least likely to agree that risk was a significant barrier to participation. Generic online searches, condition-specific online sources of information and healthcare professionals were the primary sources of information, with a high degree of trust in the information provided by professionals.

4.4.1 Recommendation 3

Public communications and engagement should have a greater emphasis on informing and empowering people at the point of care or enquiry, to enable discussion of trials with clinicians. Specifically:

- Integration of trial information, participation information and concrete means of enquiry into online service information, consultant profiles and into appropriate printed material, e.g. patient information, newsletters etc.
- In addition to active engagement and materials for patients, resources for their family and friends should be implemented to enable discussion and wider participation in relevant research.
- Clear information on risk and the nature of trial treatment options, including clear statements on the degree of uncertainty of potential benefits and treatment allocation, should be prominent in all communications, engagement and conversations.

4.5 Time and fitting participation into life is a concern

Enabling participants to fit research participation around work and home commitments is likely to support greater participation. Concerns over time commitments needed to participate in studies, including taking time out of work and fitting such activity into daily/family life were significant barriers to participation.

4.5.1 Recommendation 4

Changes to clinical research delivery to improve convenience and flexibility for participants, alongside interventions that lower the practical threshold to participation should be investigated and evaluated. Specifically:

- Expansion of out-of-hours/evening, community and offsite research clinics.
- Engagement with major local employers re. schemes to enable onsite participation, or release for attendance at hospital/community clinic should be explored. This includes NHS organisations themselves.

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Further information

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