Starting with the baseline: Protected characteristics project

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Background

- Individuals from many minoritised communities and from areas of high deprivation are under-represented in research
- Under-representation in participation reduces the generalisability of findings, exacerbates poor patient outcomes, and increases treatment costs
- Very little data on PCs or caring responsibilities is routinely collected clinically or from research participants, making it impossible to identify under-represented communities/groups
- Comprehensive baseline data is needed to agree KPIs to monitor participation in research and to assess the effectiveness of programmes to address inequalities in participation

Aims:

- To establish an efficient process to collect data on PCs, caring responsibilities and deprivation from all participants in NIHR research across our ICB
- To develop KPIs to be able to measure effectiveness of interventions to widen research participation.

Protected Characteristics

- Age
- Disability
- Race/Ethnicity
- Religion/ Beliefs
- Sex
- Gender reassignment
- Sexual Orientation
- Marriage
- Pregnancy

Also included

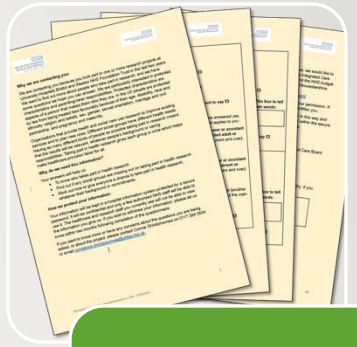
- Deprivation (IMD)
- Caring Responsibilities

Questionnaire development:

NIHR recommended diversity data questions (2022)

4 focus groups- public contributors

Co-development



End result!

Establishing distribution processes of the questionnaire:

- Needed to be scalable and as easy as possible for research teams that minimises manual data entry
- Use REDCap server which sits behind NHS firewall (many large trusts have them).
- Use REDCap to send emails and commercial provider (eg Twilio) for SMS.
- In both cases simple explanatory text in email/SMS and a URL to click on to respond to questionnaire so data entered directly into REDCap
- Consider postal questionnaires for those without emails and mobile contact but resource intensive if large numbers

CRF Pilot phase 1

- Co-designed PC questionnaire with multiple focus groups of patients and public
- Community engagement before finalising protocol
- Sent to all participants in studies delivered at UHBW CRF over the last 2 years
- Vaccine trials (Covid-19, CMV, E-coli, RSV)
- 582 participants, all over 18 years old
- Sent URL by email/text and a reminder two weeks later
- 9 individuals contacted by post since no email/text
- 69% response rate
- >98% provided postcode (IMD)
- >99% consented to linkage to BNSSG PHM dataset

Phase 2

Use funding from NHSE to:

- Roll out data collection to all research study participants at regional teaching hospital of all ages from January 2022 – December 2023
- Anonymised the request to participate to minimize data breaches
- Co-design KPIs to monitor PCs, caring responsibilities and IMD profile of participants in research and evaluate interventions that aim to improve research participation by under-represented groups/communities

Combined Phases 1 and 2

Age	BNSSG	Phase 1 and 2
0-15	16.8%	7.0%
16-29	20.0%	8.7%
30-39	16.5%	15.9%
40-49	13.2%	9.7%
50-59	11.9%	14.1%
60-69	9.5%	17.1%
70-79	7.4%	21.3%
80+	4.6%	6.4%

Ethnicity Phase 1 and 2	
Asian	2.2%
Black	1.4%
Mixed	1.6%
White	93%
Arab	0.3%
Prefer not to say	0.7%
Other	0.9%

Total non-white 6.3%
(BNSSG 14%)

IMD decile	BNSSG	Phase 1 and 2
1	15.4%	7.1%
2	14.4%	6.6%
3	11.4%	7.6%
4	11.8%	8.3%
5	10.3%	8.3%
6	6.1%	10.1%
7	11.4%	14.4%
8	7.2%	13.0%
9	5.7%	12.0%
10	6.1%	12.7%

KPIs

- Locally defined key performance indicators (KPIs) to monitor participation in research by under-served communities and to evaluate the effectiveness of interventions being implemented

- Produced using results from phase 1 and 2. Involved members from multiple community groups, religious groups, LGBTQ+, WECIL, Black Mothers Matters, Health Research Ambassadors and YPAG Bristol:
    - Must provide evidence of inclusivity in research design and recruitment methodologies
    - Improve participants' experiences
    - Monitor how representative of the target population the workforce is
    - Match research participation to geographical population and demographics
    - Provide evidence that alternative ways of recruitment are used to enable people from under-served communities to participate

Challenges in questionnaire roll-out:

- Inconsistencies between organisations on basic data that is collected for research participants.
- Variation in awareness of consenting process and how some studies fall under CAG
- Organisational differences on how the project is classified (service improvement versus research)
- Need for flexibility as processes will vary between the sites involved, depending on whether they are primary custodians of data

Thank you and Keep in touch

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