NIHR | Imperial Biomedical Research Centre

Public Involvement to inform the NIHR Imperial Biomedical Research Centre Reapplication 2022 to 2027: full report

Contents

Foreword by Sandra Jayacodi (Lay Chair of the Imperial BRC Public Advisory Panel)

"This reapplication process has taught us a lot about improving how we do things. It showed us that there are so many opportunities for meaningful and inclusive public involvement (even in a pandemic!) to ultimately enhance our health and improve our quality of life. We also learned how to work in a more collaborative way and in challenging circumstances."

Executive Summary

Introduction

The National Institute for Health Research (NIHR) Imperial Biomedical Research Centre (BRC) is a collaboration between Imperial College London and Imperial College Healthcare NHS Trust (ICHT) currently funded until 2022. To enhance our existing public involvement[1] activity, we undertook additional activities to support the development of new and existing research Themes for the purpose of the BRC reapplication for 2022 to 2027.

Our public involvement activity is a crucial component of the development of BRC's proposed programme of research, helping us to understand priorities and unmet needs of the population in North-West London (NWL), and the relevance of the proposed Themes and research programmes to those needs. It also provided recommendations for how best to involve the local population in BRC research to ensure inclusion of those from currently underrepresented and underserved communities.

Activities undertaken

The public involvement activities were facilitated by the Patient Experience Research Centre (PERC) (a core facility of the Imperial BRC) and the Imperial BRC Public Advisory Panel (Panel) and involved a range of activities undertaken from November 2020 to September 2021. The public involvement activities included (see **Appendix 1**):

- a series of 14 online group discussions with Theme researchers, Panel members and members of the public involving 245 people
- three online surveys receiving 1190 survey responses
- specific activities with 28 local community members
- Panel recommendations to the ICHT Research Committee about PPIE in BRC governance
- strategic advice provided by ICHT Strategic Lay Forum (SLF) and Panel members on the overall application including reviewing plans and materials for the public involvement activities
- ICHT SLF and Panel members shortlisted candidates and sat on interview panels to appoint Theme leads and co-leads to ensure that the recruitment process and the candidates addressed public involvement plans

Recruitment of underrepresented voices

In order to address underrepresentation in research, we tailored our recruitment approaches to invite members of the public who: had not previously taken part in our public involvement activities; and the voices of those often underrepresented in research through for example, establishing new contacts with communities and third sector organisations (see **Appendix 2**). This particularly impacted our group discussions which included people of diverse ages (range 13 to 93 years) and ethnicities (58% non-white). See **Appendix 2** for further details.

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[1]We use the NIHR INVOLVE definition of public involvement as "research being carried out '**with**' or '**by**' members of the public rather than '**to**', '**about**' or '**for**' them" - https://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/

Priority Areas identified for all Themes

- Long term conditions and comorbidities which have a large impact on the local population and pose significant challenges for research.
- Mental health as a specific focus and as a factor influencing other conditions.
- Addressing the multiple factors influencing health burdens including specific conditions, e.g. obesity (and linked to fertility), diabetes, COVID-19, digestive diseases, and non-alcoholic fatty liver disease, which were in part seen as linked to social factors and lifestyle.
- Air quality as both a key factor in worsening of conditions such as asthma, and as a broader environmental factor linked to mental and physical health and wellbeing.
- Using artificial intelligence to monitor response to treatments, identify at risk patients, and improve patient experience which informs the BRC thread of *precision medicine*.
- Finding ways to improve disease, including the precision and timing of diagnosis, particularly for conditions which are often missed or delayed (e.g. endometriosis, myalgic encephalomyelitis/chronic fatigue syndrome, inflammatory bowel disease), which are linked to the BRC threads of *early diagnosis* and *precision medicine*.

See **Appendix 3** for priority areas linked to specific Themes.

Cross cutting issues

- Prevention of both common and rare diseases, for adults and children, to reduce the burden of ill health in the local population. This is linked to the potential for precision medicine, for example with molecular phenomics and digital tools that better communicate risk (*precision medicine* and *digital health* BRC threads).
- *Early diagnosis* and intervention.
- Developing communication for health promotion and research awareness through a range of channels; reaching different communities, with a specific call to address the digital divide that may be leading to further exclusion of some vulnerable groups.
- Transparent and secure use of patient data for health research and preventing access by private companies for profit.
- Support for the development of *digital health* tools to reduce fragmentation of data and support communication, self-management, and remote monitoring.
- Using artificial intelligence to maximise the learning from data and as decision tool (rather than to make decisions).
- Addressing inequalities as determinants of health, for example poor housing, air quality, or access to early diagnosis and prevention.

Recommendations for future public involvement

Throughout these public involvement activities, many ideas were suggested about how to improve future public involvement and include:

- That a PPIE strategy should be tailored to relevant populations, and include communication using different media including radio, TV and face-to-face to reach diverse communities.
- To widen involvement and participation, clear concise information and tailored messaging is important for different communities including in different languages, for children and young people as well as adults.
- Public involvement should be included in governance, appropriately resourced, and have a public representative embedded in Themes to attend management meetings and promote a culture of involvement among researchers.
- Suggestions were made about how to identify those with lived experience, for example through primary and secondary care networks, pharmacies, community champions and third sector partners such as charities.

- Public involvement is important throughout the research cycle, starting with identifying unmet needs and research priority setting through to co-development and co-production of research and implementation where possible.
- The public should be integrally involved in ensuring that datasets are used for the public benefit, to provide review of ethical appropriateness of research and to inform decision making and consent processes for data access.
- It is critical to provide feedback at all stages of research especially to participants of research studies without whom the research could not take place.

See below for further detailed recommendations.

How we used the insights

Insight reports summarising key points from the activities were made available to Theme leads, the BRC Executive and the public who took part in the involvement activities. These reports are summarised here and were used to shape the BRC application and have specifically informed the Patient and Public Involvement, Engagement and Participation section, including proposed public involvement in governance and resourcing. Through the process of conducting these activities, we have established a wider and more diverse network of contacts for ongoing involvement.

We would like to thank all those members of the public who gave their time and thoughtful insights through these activities, and the researchers who engaged enthusiastically in the process.

Maria Piggin, Halle Johnson, Sandra Jayacodi, Helen Ward. "*Public Involvement to inform the NIHR Imperial Biomedical Research Centre Reapplication 2022 to 2027*". Imperial Patient Experience Research Centre, October 2021

Main areas of insight obtained from public involvement activities

The following four main areas of insight were identified across the public involvement activities and the main themes, suggestions and recommendations from each area of insight are set out below under each heading:

1. Priority areas identified for all Themes
2. Cross cutting issues
3. Feedback relevant to particular research areas
4. Recommendations for future public involvement

1. 2. Research priorities identified for all Themes

Across our public involvement activities, the following research priorities and unmet needs were identified. Please see **Appendix 3** for the key insight summaries for each of the involvement activities.

Long term health conditions: lung health, diabetes, autoimmune diseases, and other long-term and complex conditions were identified as important. This was especially relevant due to the increased prevalence in the local community of these conditions and the need to improve treatment and enable individuals to self-manage these conditions

Co-morbidities: Key clusters of disease included diabetes together with cardiovascular diseases; allergies, immunology and the mechanisms of autoimmune diseases, obesity linked with deprivation; obesity and high BMI underlying many conditions; frailty; inflammation; and environmental aspects. In addition the treatment of one condition which causes another condition e.g. medication for heart disease leading to kidney failure. Mental health was considered to be linked to all conditions. There was a need to look at intersectionality around sexuality, religion, socioeconomic status rather than just looking at people in different silos e.g., male or female. Lifestyle factors were also considered relevant including those which did not necessarily link to socio-economic status.

Mental health: including early detection of conditions affecting children and young people (including schizophrenia and bipolar disorder) and the role of genetics or external factors in these conditions. Identifying biomarkers for mental health. Dementia/Alzheimer's were considered more prevalent (particularly with COVID 19). The mental health impacts of people returning to a 'post pandemic normality' after being "institutionalised" by lockdown was also identified.

Digestive diseases*:* intestinal microbiota transplants are favoured as being less invasive than other procedures. Liver disease was considered very relevant due to alcohol use and an aging population. There is a need to explore the relationship between gut health and other areas of health including non-alcoholic fatty liver disease as well as obesity and related factors like pre/post menopause. Another need to develop appropriate strategies for the age "spikes" in IBD between 20 and 40 years and over 60 years.

Diabetes (Type 1 and 2) and in particular, adolescent diabetes. Exploration of: different forms of insulin administration; the link between diabetes and diet in ethnic groups; and Type 2 diabetes are needed;

Obesity: reducing obesity in children and young people, understanding the role of physiological and psychological factors on weight-gain, weight-loss and fertility; exploring the complexity of weight and fertility; the role of social, cultural, genetic and environmental factors on weight; and greater awareness around stigmatisation and mental health impacts linked to obesity and eating disorders.

Fertility: research into Polycystic Ovary Syndrome (PCOS), personalised approaches to fertility support, treatment and interventions, the role of cultural factors on fertility, and the impact of health promotion behaviours vs the impact of weight loss.

COVID 19: the impact of COVID 19 on child development, the learnings from COVID 19 e.g. positive outcomes which can be applied more widely e.g. mask wearing to avoid winter infections, successful vaccination programmes. Research into pre-existing respiratory illnesses e.g., asthma in light of the more severe impact of COVID 19 on these patients.

Non-alcoholic fatty liver disease (NAFLD): in light of no accurate method of diagnosis or treatment, , improving diagnosis through use of artificial intelligence was supported and improving treatment of NAFLD through hormones.

Real world evidence/digital health/Artificial Intelligence:

Three multichoice polls were undertaken in online discussions which identified (when attendees were asked to choose their top 3):

- the areas of research where routinely collected health data (as real world evidence) should be prioritised as: cancer (64%) then mental health (50%)
- the areas which would most benefit from the use of AI and should be prioritised as: "Monitoring responses to treatments" (76%), "Identifying at risk patients" (59%) and "Improving patient experience" (53%)
  the areas on which digital health research should be focused to improve health and care as: "Understanding disease", "Improving diagnosis" and "Treatment and prevention" (which all received 63% *votes)*

Respiratory: Identifying the causes of lung disease in early life, understanding how pollution impacts the lungs, and developing new treatments for patients with advanced lung disease were cited as the top priorities for respiratory research. Air quality and its effects on exacerbations, (particularly in light of COVID 19) and identifying the cause of, and developing new tests for, pre-school/childhood wheeze were considered important as were the respiratory health care needs of mental health patients, collaborations in rare diseases and the psychological impact of restricted breathing e.g., in asthma.

Improving disease diagnosis: for diseases which often result in delayed and missed or incorrect diagnoses (e.g. Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) mistaken for depression; endometriosis mistaken for inflammatory bowel disease).

2. Cross cutting issues

Across our public involvement activities, the following cross cutting issues were identified. Please see **Appendix 3** for the key insight summaries for each of the involvement activities.

Prevention:

- Strategies to prevent both common and rare disease for adults and children were considered vital to improve the health of the local community and reduce costs and pressures on the NHS including health promotion and education (which advises and informs patients how to remain healthy (e.g., nutrition) and can enable patients to take care of their own health).
- Digital tools, as well as the use of advanced technologies, such as molecular phenomics were perceived to be a useful way to assist with prevention of health conditions by providing health management guidance as well as identifying at risk patients.
- Areas where prevention was particularly highlighted were obesity, Type 2 diabetes, non-alcoholic fatty liver disease (NAFLD), digestive diseases and respiratory conditions caused by environmental factors.

Education and health promotion:

- Although considered important for prevention, education and health promotion were considered to crucial to sit alongside all research programmes and should be implemented through different mediums and in different languages including infographics, through schools, daily newspapers, leaflets, social media, radio, and TV as well as linking to national health campaigns.
- Areas of high importance were obesity**,** cancer, the genetic causes of certain diseases to remove stigma, lifestyle impact on disease risk and 'invisible' conditions/issues such as NAFLD, mental health and infertility.
- Engaging the wider public was considered to be easier for more prevalent conditions e.g., digestive diseases.
- Educating and supporting people to use digital tools, which could be used to share information and advice, would assist to minimise the digital divide.

Early intervention:

- Early intervention was considered important in all research Themes.
- Linked to this was the need to identify potential health risks or risks of disease as early as possible so interventions (including lifestyle and treatment interventions) could be implemented.

Transparency and assurance required about the security and use of data

- This was of particular concern especially following recent negative publicity about the use of patient data by NHS Digital.
- The need for anonymisation, data security, consent, and the ability to opt out of their data being utilised was emphasized for use of all data including restricting third-party access without consent.
- Use of anonymized data by private companies and the financial gain from the sale of patient data by the NHS, (if not filtered back to patients to whom the data belongs) were not generally supported.
- The risk of hacking and ransom attacks were a concern in light of recent similar occurrences.
- Greater use of existing historical datasets (eg the Wynn Database of metabolic risk factors) and cohorts (e.g. Lolipop, Airwave studies) for further research*,* was supported when the

purpose was to improve clinical care, research, and population health. Its use was also supported subject to: anonymisation and appropriate data security; appropriate communication about the research; use of other recognised data sources; and the need for data quality guidelines.

Developing and utilising digital health tools:

- Reduction of data fragmentation across the health system was highlighted as a priority area which was required to be addressed
- Utilisation of digital tools such as the development of easy- to- use patient portals/apps and undertaking of remote monitoring could be valuable in overcoming the current fragmentation of data.
- Digital tools were also considered valuable to address and monitor sensitive subjects including mental health.
- Remote monitoring was considered important for:
  - future healthcare in light of recent examples supported by the public e.g. the Zoe COVID symptom monitoring app. However digital poverty, digital exclusion and accessibility e.g., translation, need to be addressed (e.g. through access, education and support) so "no one is left behind".
  - to overcome inaccuracies in medical records which currently exist. Patients and their families could record, update and correct (where necessary) their own health data, access test results and scans and receive reminders to aid decision making and self-management.
- Face-to- face care should not be replaced by digital tools as it is still important.
- A hybrid model of care comprising face-to-face, and digital health was needed to: ensure those affected by digital poverty and lack of technical knowledge were not excluded; and for situations where face-to-face assessment is more appropriate and preferable for patients.
- *Real world evidence*: there was an expectation that real world evidence was already being used for research and should be, with benefits including speed and inclusion of a wider representation of the population e.g., children and pregnant women, compared to clinical trials. It was considered important to consider that some datasets may be biased and underrepresent certain communities. Consent should be requested to use real world evidence in studies and to provide third parties access to it.
- *Artificial intelligence (AI):* was seen as a beneficial, especially to: identify potential health risks and facilitate diagnosis in genetic and rare conditions within families; improve resourcing in healthcare (including clinical decision making); and to improve patient experience e.g. developing a more accurate and non-invasive diagnostic test in NAFLD. However, transparency and consent were considered essential. Public trust and understanding of AI needs to be further established and medical professionals need to be confident and upskilled to use AI and to communicate its findings appropriately to patients. Concerns about AI included the accuracy and validity of AI and how this is monitored, the quality of the data used in AI and how representative it is which led to the suggestion that AI should be used as a tool rather than to make a final decision and that a patient's relationship with a healthcare professional was still important. Concerns were also expressed about the consequential burden on the NHS from additional conditions to be identified by AI as well as doctors placing too much reliance on it to make decisions

Addressing health inequalities:

- This was considered of paramount importance across all Themes especially the need to understand environmental, social and cultural factors through using relevant data in a healthcare setting e.g., infections caused by damp houses and linking existing datasets.

- Not reinforcing historical health inequalities by inadequately addressing rare or complex diseases which attract less research and funding was identified.
- Inequitable access to healthcare, support and treatment were also raised as issues.
- Real world evidence studies were seen as a way to involve those currently underrepresented in research more widely.
- The impact of health inequalities and inequity on multimorbidity was considered significant.
- Identifying and understanding communities health needs could be assisted through digital health and measuring environmental factors digitally if digital exclusion is addressed.

Personalised medicine:

- There was an expectation that personalised medicine was already taking place for both adults and children and that an integrated care approach should be taken to this.
- It was emphasised that people should be treated as 'individuals' e.g. weight loss, interventions should be personalised to each individual, and communication about health risks should be given on an individual level (rather than group).
- The potential for studies including social, genetic and environmental determinants of health to offer "personalised" interventions (e.g. treatments, prevention strategies) was seen as beneficial particularly for at risk groups. However, participation in such studies would be conditional on sufficient information about the research and data security being provided together with follow on care and support.

Collaboration with other stakeholders both across Imperial, North West London, and nationally:

- To avoid duplication and to maximise outcomes for patients this was considered very important e.g., with the NIHR Applied Research Collaborative North West London (ARC NWL) re multimorbidity and mental health and with Great Ormond Street Hospital (GOSH) for paediatric care.

Need for plain language to effect inclusive/accessible research:

- Lack of understanding by the general public and especially underrepresented and underserved communities as to the relevance of research to them and their ability to take part in it was highlighted. This included understanding the meaning of: real world evidence studies, artificial intelligence, primary, secondary, and tertiary care, multimorbidity etc

Need to build trust and confidence in underrepresented/underserved communities about healthcare and science especially since COVID-19.

Need to undertake research into patient participation and what motivates people to stay on trials/studies across different medical conditions to help support future research.

3.Feedback relevant to particular research areas

Across our public involvement activities, the following feedback relevant to particular research areas was provided. Please see **Appendix 3** for the key insight summaries for each of the involvement activities.

Brain Sciences*:* The use of technology in young people's mental health research should be co-developed with young people from the outset and **schools** should be directly involved.

Digestive diseases*:* Ensure the language used about this area is more acceptable e.g., use "gut" instead of "bowel" and create a platform where people can discuss and raise awareness about these areas of heath.

Digital Health: Reduce the digital divide by ensuring underrepresented communities have access to digital health tools which are easy to use and include the translation of apps into different languages. Provide adults and children with access to their health data to improve its quality. Algorithms need to be codeveloped in a meaningful way and be responsive to both clinicians and patients.

Surgery and cancer: Raising awareness of the increased risk of cancer across Black and Minority Ethnic communities was considered critical, as was addressing stigma and discrimination across communities regarding cancer. Services need to be culturally sensitive and accessible and working alongside the community as well as with GPs was suggested.

Metabolic & Endocrine: The impact of weight (and infertility) on mental and psychological health was identified as extremely important. Clinics and interventions should: be specific and personalised to each individual, include referral to, or provision of support services such as mental health or nutrition support, provide increased mental health support when navigating weight and fertility services as well as throughout treatment and pregnancy, be person-centred and look at the problem holistically, including any underlying factors (both physiological and psychological) which could be contributing to infertility, and give patients a choice and a voice in their treatment. Researchers and clinicians were urged to take a more balanced view on risk, with public contributors noting the harm which negative messaging around risk may cause to people. Individuals also suggested further areas of focus including prevention, exploring the role of genetics and ethnicity on diagnosis, development of screening programmes for NAFLD and exploration of other contributing factors including gut health, diet, and weight.

Multimorbidity: It was recommended that both qualitative and quantitative research should be utilised to add strength to this research and utilising research from countries which may also be relevant for the North West London population was supported. Communication between healthcare professionals was seen as paramount and that improved sharing of information and communication between both healthcare professionals and between different departments would improve patient experience as would timing of appointments to avoid rush hour on public transport and allow the use of Freedom Passes. Quality of life and quality of death (especially for family members) were also considered to be priorities for those with multimorbidities.

Respiratory*:* Due to the prevalence of respiratory conditions in communities, hosting People's Research Cafes was recommended to engage and involve communities

Social, Genetic and Environmental Determinants of Health*:* This Theme has unique opportunities to: dispel myths about certain conditions (e.g. that type 1 diabetes is caused by too much sugar and all liver disease is caused by alcohol abuse);understand the variety of factors which may cause disease including social, genetic and environmental, , (and potentially human error factors); as well as

educating the public more broadly to address the apportionment of blame to individuals who have certain conditions which have a genetic cause. A predictive tool to help identify children at risk of disease was recommended. Communication about personalised risk of disease should be sensitive and in person or over the phone rather than in writing and at a time when the recipient chooses. It would also be beneficial if the information was communicated by someone known to the patient who could explain how their risk was identified and the next steps. Support would then need to be provided to offer people coping strategies including talking therapies.

Molecular phenomics: this research should be used to; help improve disease diagnosis of conditions commonly misdiagnosed or prone to delayed diagnosis; to assist adults and children to remain healthy for as long as possible (including prevention strategies); and to provide detailed information about their health status but with appropriate support and explanation depending on the seriousness of the condition or risk identified. Live health status updates could aid self-management and early intervention for those at risk.

4.Recommendations for future public involvement

Across our public involvement activities, the following recommendations for undertaking future involvement in North West London was provided. Please see **Appendix 3** for the key insight summaries for each of the involvement activities.

At BRC Theme level

- Develop a PPIE strategy appropriate to the relevant population group so that local communities are engaged in different ways including radio stations, TV and face-to-face especially with communities who are communicate orally.
- Include public involvement in Theme governance; a public representative should be embedded in the Theme who should attend Theme management meetings. A Theme staff member should be accountable for PPIE and each Theme should ensure it resources PPIE appropriately.
- Embed a culture of meaningful public involvement in researchers who undertake it as part of every project including building capacity in public involvement.
- Ensure communication and coordination in order to integrate public contributors into research teams including keeping them regularly updated.

Information Provision

- Provide clear concise written information and tailored messaging when undertaking dissemination among different communities including in different languages. This should include visual information including videos to explain research studies and/or participation.
- Utilise GPs and community healthcare centres to share information about research/opportunities
- Emphasize the benefits of the research
- Link with other ongoing health and prevention campaigns e.g., diet and obesity.
- Undertake a media campaign to raise awareness of research generally and prevalent conditions such as NALFD and obesity

Who to involve

- Involve people with lived experience of research areas (and those at risk), carers and wider family members.
- Include ethnically diverse communities, by engaging with community leaders.
- Involve other stakeholders including social services for both adults and children, allied health professionals, primary care and community healthcare contacts, local government and public health officials, maternity, and health visiting teams.
- Ensure the involvement of young people: engage children and younger people including through schools, young childhood education facilities, social media, Tik Tok Instagram, podcasts

Where to find people to involve

- Identify those with lived experience by utilising hospital consultants/doctors and their clinics to identify patients to involve (especially because patients are unlikely to know they could be involved in research). Utilise local hospitals, pharmacies, and primary care networks e.g. GPs with pre-existing relationships with community members
- Partner with third sector groups, charities and third sector organisations.
- Utilise personal networks and social media including Instagram.
- Link to national prevention groups and utilise community champions.
- Utilise existing Imperial College resources and networks e.g., the White City community and VOICE

How to involve people

- Involve the public early and meaningfully throughout the research cycle
- Undertake public involvement appropriate to each research area including co-development and co-production with shared power and influence where appropriate
- Ask patients what their unmet needs are and undertake research priority setting activities
- Ensure reciprocity in the involvement relationship including providing training to public contributors.
- Build relationships between patients and researchers to gain trust and acceptability of research.
- Acknowledge the value of public contributors through building a community with the same purpose
- Use schools and education facilitates to raise awareness of research and utilise their resources e.g. Wi-Fi and existing relationships with children and parents to access potential research participants and to conduct research
- Involve the public in ensuring datasets are used for the public benefit, to provide review of ethical appropriateness of research and to inform decision making and consent processes to access databases
- Provide feedback at all stages of research especially to participants of research studies without whom the research could not take place.

Appendix 1: Public involvement Activities and Demographics

1.1 BRC Public Advisory Panel Meetings

Research areas	Molecular Phenomics	Brain Sciences / Metabolic Medicine	Digital Health / Metabolic Medicine	Cardiovascular/ Digestive Diseases	Children & Young People/Respiratory	Multimorbidity
Date	05.11.20	21.01.21	16.02.21	08.03.21	08.04.21	08.09.21
Number involved	12	11	16	14	14	11
Age range	39-92	39 - 93	19 - 93	19 - 93	39 - 93	39 - 93
Gender	Female: 8 Male: 4	Female: 7 Male: 4	Female: 11 Male: 5	Female: 9 Male: 5	Female: 9 Male: 5	Female: 7 Male: 4
Ethnicity	White: 5 Asian: 3 Black/African/Caribbean: 3 Other: 1	White: 5 Asian: 2 Black/African/Caribbean: 3 Other: 1	White: 8 Asian: 3 Black/African/Caribbean: 3 Other: 1 Not provided: 1	White: 6 Asian: 4 Black/African/Caribbean: 2 Other: 1 Not provided: 1	White: 7 Asian: 4 Black/African/Caribbean: 2 Other: 1	White: 6 Asian: 3 Black/African/Caribbean: 2

1.2 Online Public Discussion Sessions

Research areas	Digital Health	Digital Health	Metabolic Medicine	Digital Health	Social, Genetic & Environmental	Metabolic Medicine	Metabolic Medicine	Molecular Phenomics
Topic (If applicable)	*Building digital healthcare in NWL*	*Real World Evidence*	*Using the Wynn Database for Metabolic Research*	*Artificial Intelligence*		*Weight and fertility*	*NAFLD*	
Date	07.07.2021	21.07.2021	29.07.2021	04.08.2021	01.09.2021	02.09.2021	06.09.2021	14.09.2021
N involved	25	26	18	19	22	20	9	28
Age mean (range)	43 (17-77)	41 (14 – 88)	49 (31-81)	43 (19-88)	41 (18-75)	33 (19 – 49)	42 (23 – 72)	37 (17 – 75)
Gender (n)	Female: 15 Male: 10	Female: 18 Male: 6 Non-binary/ Gender variant: 1 Other: 1	Female: 10 Male: 7 Non-binary/ Gender variant: 1	Female: 13 Male:5 Non-binary/ Gender variant: 1	Female: 14 Male: 8	Female: 16 Male: 4	Female: 5 Male: 4	Female: 19 Male: 8 Not provided: 1
Ethnicity (n)	White: 7 Asian: 10 Black/African/ Caribbean: 6 Other: 2	White: 10 Asian: 13 Black/African/ Caribbean: 2 Other: 1	White: 13 Mixed/Multiple: 1 Asian: 3 Other: 1	White: 5 Asian: 6 Black/African/ Caribbean: 6 Other: 2	White: 10 Asian: 7 Black/African/ Caribbean: 4 Not provided: 1	White: 8 Mixed/Multiple: 2 Asian: 6 Black/African/Caribbean: 2 Other: 2	White: 2 Mixed/Multiple: 1 Asian: 2 Other: 4	White: 3 Mixed/Multiple: 1 Asian: 15 Black/African/Caribbean: 2 Other: 4 Not provided 3
New to research?	Not provided	Yes: 3 No: 9 Don't know: 2	Not applicable	Yes: 5 No: 9 Don't know: 1	Not applicable	Not provided	Not provided	Not provided

		Prefer not to say/no response: 12		Prefer not to say/no response: 3				
No. new to Imperial? (data from individuals who completed feedback form)	**10/14**	**4/7**	**5/9**	**3/9**	**8/10**	**4/6**	**Not provided**	**3/9**

1.3 Public involvement surveys

Research areas	Respiratory	Involving children, young people and families in our research	Molecular Phenomics
Timeframe	July – August 2021	August – September 2021	August – September 2021
N involved	116	51	1023
Experience of respondents	• Living with a respiratory condition: 49 • Friend/family/carer of someone with a respiratory condition: 20 • Member of the public interested in respiratory health: 18 • Other: 9 • Not provided: 20	• Parent of a child/children: 41 • Caregiver (e.g., grandparent): 9 • Member of the public interested in child health: 2 • Other: 1	Not applicable
Age mean (range)	61 (23 – 92)	45 (30 – 66)	70 (13 – 93)
Gender (n)	Female: 69 Male: 28 Non-binary/ Gender variant: 1 Other: 2 Not provided: 16	Female: 45 Male: 4 Not provided: 2	Female: 606 Male: 400 Non-binary/ Gender variant: 1 Transwoman: 1 Not provided: 18
Ethnicity (n)	White: 81 Mixed/Multiple: 4 Asian: 10 Black/African/Caribbean: 5 Other: 3 Not provided: 13	White: 28 Mixed/Multiple: 4 Asian: 4 Black/African/Caribbean: 4 Other: 4 Not provided: 5	White: 911 Mixed/Multiple: 12 Asian: 51 Black/African/Caribbean: 9 Other: 20 Not provided: 23

1.4 Other public involvement activities

Theme (s)	**Digital Health**	**Social, Genetic and Environmental**	**Surgery and Cancer**	**Surgery and Cancer**	**Surgery and Cancer**
Description	*Presentation to Action on Disability local group*	*Presentation to REACT project advisory group*	*Discussion with unrepresented community member with lived experience of cancer*	*Discussion with unrepresented community leader*	*Online discussion with existing Imperial Public Involvement Group for Cancer*
Date	14.05.2021	20.05.2021	03.09.2021	17.09.2021	22.09.2021
N involved	10	9	1	2	6
Purpose	Engaging with underrepresented individuals living with various impairments through Action on Disability to help us shape how we can address healthcare inequalities linked to the Data/Digital Divide	To obtain initial feedback on Theme plans and ideas from the REACT project advisory group. Discussion on priority areas for this Theme as well as key considerations in terms of communication and engagement with communities.	To understand the experiences of this underrepresented community member who has previously taken part in a cancer clinical trial and to obtain their thoughts and ideas on areas which the Theme should be pursuing and advice on how to engage with underrepresented communities.	To discuss current issues facing this community in relation to cancer and to obtain advice on how to continue to engage and work with them across surgery and cancer's research and activity.	To obtain feedback on the Theme's research ideas and to obtain advice on how to continue to work with patients, public and North West London community going forward.

Appendix 2: Approach to Recruitment to Public Involvement Activities

2.1 Imperial BRC Public Advisory Panel meetings

Feedback was provided by the Imperial BRC Public Advisory Panel to the following Themes' plans:

- Brain sciences
- Cardiology
- Digestive diseases
- Metabolic and Endocrine
- Metabolic Phenotyping
- Multimorbidity
- Respiratory
- Children and young people

Each feedback session was one hour and comprised two Theme researchers presenting their initial research plans and ideas to the Panel, answering their questions, and eliciting Panel members' feedback (in smaller discussion groups) on up to three questions relating to their research or public involvement plans or requests for recommendations on conducting public involvement.

2.2 Online public involvement discussions

- Digital health
    - o Digital health generally – 7 July 2021
    - o Real world evidence – 21 July 2021
    - o Artificial intelligence – 4 August 2021
- Metabolic and Endocrine
    - o Wynn Database -29 July 2021
    - o Weight and fertility – 2 September 2021
    - o NAFLD – 6 September 2021
- Metabolic Phenotyping – 14 September 2021
- Social, Genetic and Environmental Determinants of Health - 1 September 2021

Online discussions were usually hosted for 1.5 hours on weekday evenings (usually from 5pm to 6.30pm) to enable those working to take part. We explored holding weekend sessions however identified that these were not as popular after COVID 19 restrictions had been lifted.

The aim of the online sessions was to:

- introduce the Imperial Biomedical Research Centre and the proposed Theme's research priorities (5 mins)
- provide an example of research that the Theme's researchers had already undertaken or would undertake (25 mins)
- give attendees an opportunity to ask questions (15 mins)
- facilitate small group discussions of up to 10 members of the public on up to three questions about which researchers were keen to hear the public's views and which questions varied for each Theme (45 mins):

The following dissemination routes were utilised for both the online discussion groups and the survey invitations

- the North West London Clinical Commissioning Group (CCG) Engagement Manager posting opportunities on the online "Nextdoor" platform and the Citizens Panel
- the Imperial College London Societal Engagement team's mailing list of White City community members
- requesting members of the Imperial BRC Public Advisory Panel to disseminate it to communities with which they have contacts
- the Imperial College Healthcare NHS Trust's community contacts
- recent sign-ups to the PERC mailing list (not yet engaged in public involvement in research)
- members of the Imperial Young Person's Advisory Network local to North West London
- patients of clinicians whose BRC research Theme was new to the Imperial BRC
- charities linked to proposed BRC research Themes
- advertisement on the Care Information Exchange
- emails to participants on the CHARIOT register
- through the VOICE Global online platform and North West London Research Involvement Group on the VOICE Global platform
- through the PERC Twitter handle

2.3 Public Involvement Surveys

The public involvement surveys for the proposed Respiratory and Molecular Phenomics Themes were also disseminated as follows:

- **Respiratory**
  - To existing Respiratory Theme contacts ('lived experience network')
  - By the North West London Clinical Commissioning Group (CCG) Engagement Manager posting it on the online "Nextdoor" platform
  - Through Imperial College Healthcare NHS Trust (through clinical colleagues and Connecting Care for Children)
  - To existing North West London networks ("Voice" NW London group, recent PERC mailing list signups)
  - To HealthWatch Central West London (CWL) – including Young HealthWatch
  - Asthma UK PPI Group (London members)
  - Cystic Fibrosis Trust (Through their public involvement team)
  - Breathe Easy (West London groups)
  - To members of the Imperial Young Person's Advisory Network local to Northwest London
  - By asking members of the Imperial BRC Public Advisory Panel to disseminate it to relevant individuals across their wider community

- **Involving children, young people, and families in our research**
  - By the North West London Clinical Commissioning Group (CCG) Engagement Manager posting it on the online "Nextdoor" platform

- o Through Imperial College Healthcare NHS Trust (through clinical colleagues and Connecting Care for Children)
- o To existing North West London and PERC networks ("Voice" NW London group, recent PERC mailing list signups, through the PERC team)
- o To HealthWatch CWL – including Young HealthWatch
- o Through the North West London Care Information Exchange Homepage
- o By asking members of the Imperial BRC Public Advisory Panel to disseminate it to relevant individuals across their wider community
- o Through Twitter

- o **Metabolic Phenotyping**
    - o Through PERC's mailing list
    - o Through the CHARIOT register
    - o To umbrella rare disease Facebook groups
    - o To rare disease Facebook groups
    - o To European Reference Network UK patient representative Facebook groups
    - o Through Twitter

2.4 Other public involvement discussions

In addition to the online discussions above, some Themes also undertook online meetings with their existing public networks, and/or organised discussions with local community groups and/or patient representatives.

- Digital Health
    - Action on Disability young people's work experience group – 14 May 2021
- Social, Genetic and Environmental Determinants of Health
    - REACT Public Advisory Group - 20 May 2021
- Surgery and Cancer
    - Discussion with patient advocate with lived experience of cancer – 3 September 2021
    - Discussion with local community Trust – 17 September 2021
    - Imperial Public Involvement Group for Cancer– 22 September 2021

Appendix 3: Executive summaries from all public involvement activity insight reports

3.1 BRC Public Advisory Panel Feedback

05.11.21 – Molecular Phenomics

Suggestions from the group as to what the Molecular Phenomics team should research and explore:

- How can I make my body healthier?
- How do I remain healthy for as long as possible?
- What vitamins should I take?
- How do we educate the members of the public about wat you should be taking?
- How do vitamin supplements compare to vitamins naturally found in food?
- What am I genetically predisposed to that I can or cannot change? (preventative maintenance)
- Can we detect things earlier which GPs haven't spotted?
- What don't I know about my body?
- What happens if you do eat regular meals compared to when you don't?
- How does the quality of air affect my health? And how much difference does being outside make to being inside? Or on a busy road vs in a garden? What routes of behaviour should I adopt to protect myself from damage from pollution?
- Ex-cancer patient, whether or not the risk of cancer returning could be calculated and what level of risk that represents
- Annual check-up with GP should include an exploration of your metabolites
- What's the risk of you being affected by X disease at some point in the future?
- 'If you had a crystal ball at 10 years old what would you do differently'

How should the Molecular Phenomics Theme reach and engage with the public?

- Consider podcasts/WhatsApp's/BBC bite sizes on this topic.

Any other disease areas that would be important to cover?

- Sickle cell disease
- Psychological aspects (mental health) also schizophrenia and bipolar disorder (aspects that show in younger people)
- Diabetes

Comments on proposed research areas and on what the application should focus

Panel members were **broadly positive** about the proposed research areas and noted that as **childhood mental health and dementia/Alzheimer's** are much more prevalent (particularly with Covid) and were underserved and underfunded that these should perhaps take priority. **Mental health, and in particular children and young people's mental health,** was considered to be a very important area including the impact on children's education attainment and learning capability and the need to explore their family history. There was support for **the use of technology in young people's mental health research,** however it should be **co-developed with young people** from the outset and **schools** should be directly involved. **Queries** were raised about whether moods could be monitored using technology and that young people may not always be aware of their changing mood and **parents, GPs and carers needed to be involved too**. Other suggested areas of research included: understanding whether **psychiatric disorders** are a result of nature or external factors e.g., social pressures; **early detection and the role of genetics in schizophrenia**; and **stroke research** due to the link to the Parkinson's Brain Bank.

Suggestions on how to undertake further consultation with those with lived experience

The Panel suggested that **communication and coordination** was needed between each research project and in order to integrate public contributors into research teams including keeping them regularly updated. It was recommended that the Theme needs to have **a culture of researchers genuinely wanting to involve the public** including **building capacity** in public involvement. A **PPIE strategy** should be created using an iterative process which needs to be appropriate to how the Theme works. It was also recommended that **public involvement be included in Theme governance** and someone in the **Theme be accountable for PPIE**. Other suggestions were to: **involve the public early and meaningfully through the research cycle; undertake public involvement appropriate to each research area;** and to focus on **co-development and co-production** with shared power and influence. The Panel also suggested involving **carers and family members** specifically when patients lack capacity as well as **social services for both adults and children.** It was considered that further consultations could be undertaken **with population groups by involving people with lived experience** in each of the research areas including by linking with contacts' networks, NHS specialist services and their patient clinical reference groups and online patient groups. It was also suggested that **partnering** with dementia charities and third sector organisations for the reapplication would be beneficial for all parties.

Comments on proposed research areas

Panel members were positive about the proposed three main areas of research presented i.e. diabetes (Type 1 and 2), obesity (metabolic surgery and non-alcoholic fatty liver disease) and fertility (linked to weight loss and pulsatile hormones). In relation to diabetes research, they suggested focus could be placed on the following areas: **different forms of insulin administration**; **diet in ethnic groups and the link to Type 2 diabetes**; and the **importance of lifestyle factors** e.g. diet, **the importance of genetic factors and Type 2 diabetes**. They also suggested research be carried out into: obesity and **mental health**; obesity, diabetes and **exercise;** and **young people,** obesity and diabetes.

Undertaking further consultation with relevant population groups

As to suggestions on how the Theme should undertake further consultation with relevant population groups, Panel members recommended linking to **national prevention groups**, **utilising community champions**, emphasizing the **benefits of the research** i.e. to reduce the current burden of diabetes. They also suggested undertaking engagement in **schools and universities,** working closely with **communities and local government and public health officials** as well as **ethnically diverse third sector groups**. Providing **written information and tailored messaging** was considered to be important. For **metabolic surgery,** they suggested involving those who have and haven't had experience of metabolic surgery and **utilising fertility clinics and GPs** to undertake engagement about fertility including exploring issues/challenges these groups may have to assist with recruitment to studies.

Proposed public involvement plans

In terms of the proposed public involvement plans outlined in the presentation slides, the Panel members considered **project specific public involvement** to be integral. They considered that a **public representative should be embedded in the Theme** and that they should **attend Theme management meetings** and the Theme should have its **own PPIE strategy**.

16.02.21 – Digital Health

A zoom poll identified that algorithms that **diagnose new conditions and algorithms that aid clinical decision-making** were most valuable and should be prioritized by the proposed Digital Health Themes. They both received equal numbers of votes i.e. 53% (n= 9/17). Please see **Appendix 1** for more details. Panel members identified that algorithms which had the **most immediate effect** on patients were a priority including identifying disease risk, diagnosing conditions and aiding clinical decision making. However, they also considered it important that **algorithms need to be developed in a way that is meaningful and responsive to both clinicians and patients**.

When presented with a scenario about algorithms being used to determine risk of heart disease and the concerns and benefits of this, Panel members considered the **benefits** to include the assistance algorithms provide to decision making which benefits the patient. They could also see **possible uses** for algorithms which included alerts for vaccinations and National Early Warning Scores. However, the following were considered as needing to be addressed: **transparency** about, and **accessibility** to, their data, **uncovering additional health issues and communicating this ethically** to the patient and the need for follow on support, **consent is required** to use the algorithm and some patients may wish to opt out of an algorithm being used in relation to them. Patients would still want **the medical professional to have discretion** to overrule an algorithm and there is **a need for a relationship with a medical professional** whom a patient trusts.

Their concerns about algorithms being used to determine risk of heart disease or other conditions included the **limitations of algorithms** including how their accuracy is monitored, the **algorithm validity** including how comprehensive and accurate the patient record information is and the **generalisability of the data** used in the algorithm and whether it represent all members of the population,

Patient Involvement in Theme
In relation to how patients should be involved with informatics projects in the BRC Theme, panel members considered that *large and diverse groups should be involved in inclusive ways, processes should be embedded for **feedback, language used should be public facing** including providing for languages other than English, and **algorithms should be co-designed with patients.** However **public trust** needs to be built about artificial intelligence.*

Overall thoughts on the use of the Artificial Intelligence platform in clinical practice

Panel members were **generally supportive** of the use of Artificial Intelligence in healthcare generally and in this project in order to permit more objectivity and get results faster as well as to save the NHS money. However, it was noted that it was unfortunate that an **invasive procedure** had to be undertaken before Artificial Intelligence could be utilised in this example. It was considered there was a need to **understand the morbidity and mortality of NAFLD and the risk of liver biopsies** to fully understand the value of the proposed platform. The potential for an **early diagnosis** of NAFLD was seen as beneficial if it would motivate a change in lifestyle. One panel member was concerned about **potential bias** within the system if the Artificial Intelligence is only going to learn from input into the system by clinicians.

Possible concerns from point of view of patient/family member

The following potential concerns were identified by panel members: **how accurate the Artificial Intelligence platform is** at determining diagnosis and disease stage in comparison to liver experts' and if there are **any other options** for determining diagnosis and disease stage and how their accuracy compared to Artificial Intelligence; whether the project had been reviewed by an **ethics committee**; implementation of **data security** aspects; and **whether there would be acceptance of the result being determined by Artificial Intelligence** although the fact of its objectivity may assist.

Suggestions for involving patients/public in project

Suggestions by panel members for involving patients/public in the 3 year project included involving **non- NAFLD affected public and those at risk of NAFLD** as well as those with lived experience. **Carers and those from diverse backgrounds** should also be included. Their involvement should be **from the outset and throughout all the stages of the project** including at the dissemination stage and one suggestion was to involve people in evaluating [biopsy] slides of people with NAFLD after being given training. The inclusion of a **Steering Committee of patients and the public** was recommended who could be kept informed about the research and have opportunities to sense-check and advise the research team. People to involve could be **recruited through weight loss groups** and recruitment should involve the **use of clear and specific language to explain Artificial** Intelligence and **training should be provided**.

Building on and improving the existing patient reference group

Panel members considered that the existing ORBITA patient group could be built on and improved by **speeding up the translation of research** by involving patients and the public including in HTA processes. **Relationships with charities** such as the British Heart Foundation (and their resources e.g. newsletters) and **GPs** could be utilised and well as the Panel's links. Due to the high prevalence of cardiovascular disease among **ethnic minority groups,** their involvement is very important, and these groups can be reached via different mediums including community groups, public noticeboards, places of worship, religious festivals and gyms. **Groups in the population who are at risk** could also provide different insights. The Panel recommended the involvement of **carers** of patients, **young people** (through university events) and **patients treated in researchers' clinics** with known disease specific experience. Ensuring public involvement activities are **accessible to different groups** including those

who work during the day and utilising interpreters and translations for those who don't speak English. Also ensuring public involvement and research participation is **more inclusive** i.e. not just involving people who already participate in research and further excluding others by moving research to an online platform. Panel members also recommended **utilising social media more** including Instagram as well as **using videos** to explain research studies and/or participation. They also recommended **emphasizing and promoting the benefits** of research including to a patient personally.

Reporting symptoms on a smartphone

Panel responses to asking patients to report symptoms on a smartphone were broadly supportive and the Zoe app was given as a good example of doing this for COVID symptoms. However, the Panel considered that **reliable smartphone and internet access** and **support and education** (to avoid excluding people) needed to be put in place to be able to do this. One Panel member was not in favour of using a different phone than their usual mobile phone to do this. **Transparency** was also considered key with people being clearly informed about the safety and purpose of the app. One Panel member said they would need to have a **relationship with the organisation** asking for this information, know how it is relevant to them and be told what it used for. The concerns identified included that **not everyone has access to a smartphone or knows how to use one,** that **seeing people face-to-face is important** for fear of symptoms being missed by the patient**.** Other concerns were whether the **smartphone app could be translated**, whether **different smartphones' capabilities** would impact being able to do this and whether **patients would be confused** about how to report symptoms. People would also need to be **assured about the safety of their personal data** in the app.

Labelling anonymized images

Panel responses to patients' labelling anonymised images to help image analysis were **broadly supportive** and a suggestion was made to **have 'image labelling' events** which people did this in groups. However, the Panel considered the following needed to be put in place to be able to do this: their grading needed to be **anonymous**, **education** about what they were being asked to do and their **consent** provided to do this. Concerns raised included the **capability of patients to be trusted** to do such a task and the **risk of gamifying the task** which may exclude people if it is too competitive.

Improving PPIE in the cardiovascular Theme

Panel members made the following suggestions for improvement of PPIE in the Theme: **educate younger researchers in PPIE**, provide **clear concise information** for dissemination among communities, **emphasize the benefit of involvement** and **ensure reciprocity** in the involvement relationship including **providing training** to public contributors.

08.03.21 – Digestive Diseases

Comments on proposed research areas

The Panel were generally supportive of the Theme's plans and expressed that **precision medicine** was a promising development, that **faecal transplants (with an alternative name)** are less invasive than some procedures, that **liver disease is a relevant issue** due to alcohol use and an aging population and that **nutrition is a crucial issue to address at as early a stage as possible**. Other areas of research were also suggested i.e. the **relationship between gut health and pre/post menopause** as well as **prevention**. **Education** was also considered to be crucial and could be **addressed through different mediums** including infographics and daily newspapers as well as and making the **language used** when discussing these conditions more acceptable i.e. using "gut" instead of "bowel". Due to the **prevalence of these conditions**, these topics are a good way to engage the wider public in research.

Suggestions on improving engagement to address research areas

Panel members suggested: **utilising hospital consultants and their clinics** to identify patients to involve (as many patients would not know they could be involved in research) however it is important to also capture those whom it may not be as easy to speak to e.g. those needing an interpreter; identifying those affected by these conditions from **existing data including primary care data; engaging children and younger people including through schools,** social media, the Imperial Young People's Network and linking with other campaigns on e.g. diet and obesity; utilising various other mediums including **social media and podcasts** and **working with GPs** to maximise pre-existing patient relationships and to share information about IBD research/opportunities; utilising **existing patient support groups, third sector organisations and communities** including engaging with community leaders. It was noted that **sensitivity** was needed when addressing socio-economic inequalities and that **building relationships between patients and researchers** was necessary to gain trust and acceptability of research.

Suggestions on building strong public involvement in the Theme

Panel members suggested: **utilising existing Imperial College resources and networks** e.g. the White City engagement team's network; **emphasising the benefits of involvement** i.e. the possible health benefit for people in the short or long term of research; **asking patients what their unmet needs** are and **undertaking research priority setting activities** e.g. jointly with charities or third sector organisations; **establishing regular open lines of communication** with public contributors to ensure a two-way dialogue; **acknowledging the value of public contributors** through building a community with the same purpose; and **ensuring the Theme resources PPIE** appropriately in order to undertake this work.

Suggestions for engaging with the wider local community

Suggestions for engaging with the wider local community included: **identifying which communities you wish to reach** and depending on their demographics, **developing an appropriate strategy** e.g. the age "spikes" in IBD between 20 and 40 years and over 60 years, **engaging with local communities in different ways** including radio stations, videos and digital engagement e.g. the VOICE platform**, create a platform where people can talk about these areas of heath** and share their experiences, **involve carers especially of younger people** with these conditions and **utilise local hospitals and pharmacies** which have existing relationships with people and could support this engagement.

08.04.21 – Respiratory

This following is a summary of the Themes identified in breakout room discussions, more details of which are set out below.

Comments on the Theme's proposed research areas

Panel members were **generally supportive of the Theme's proposed research areas because** these covered all age groups and addressed issues relevant to a wide section of the population, including possible environmental triggers and potential disease development, exacerbations and those with acute needs. A suggestion was made to also look at **air quality and its effects on exacerbations,** particularly in light of Covid. The **importance of early intervention** was noted to identify risks and prevent conditions. The link to the other specialist health care providers across North West London was considered important in working collaboratively across North West London and **addressing health inequalities**. It was noted that historical health inequalities may be reinforced by not addressing **rare or complex diseases** which attract less research and consideration needed to be given to addressing

them. Other **research areas suggested** were: **acute chest syndrome in sickle cell disease**; collaborations in rarer diseases; the psychological impact of restricted breathing e.g. in asthma; respiratory health care needs of **mental health patients** (which were considered to be neglected); **prevention of respiratory diseases** including with reference to environmental factors including housing and pollution; asthma and the impact of the neurodevelopmental disorders (NDD) on the clinical relationship in **Autistic Spectrum Disorder (ASD)** patients**;** and research into **patient participation and what motivates people to stay on trials in different conditions.** It was recommended that the **Theme leadership included clinical staff including nurse specialists/consultants** to ensure broad perspectives. Panel members queried whether the **level of trust in AI-based prediction methodologies** had been gauged in patients and whether there may be links to, and funding available through, **the climate change agenda** e.g. through local authorities.

Suggestions on how to undertake further consultation with the relevant population groups

The Panel suggested **contacting local Breathe Easy and asthma groups and contacts** as well as **involving carers, schools** (e.g. the school nurse) and **school children,** as this is an important way to engage children from a younger age and would be important community engagement and involvement. They also suggested **consulting with underrepresented groups** in the community through GPs or patient groups and **involving allied health professionals and primary care and community healthcare contacts.** The Panel also suggested hosting **People's Research Cafes** due to the prevalence of respiratory conditions in communities and the fact that people would be interested in the research.

How to best involve patients and the public within the research and Theme

Panel members suggested: **involving patients and the public from the outset of research projects**; involving **third sector organisations and charities** e.g. Cystic Fibrosis Trust; **ensuring relationships are mutually beneficial** by providing people with information they want e.g. how to improve allergies and if they are breathing clean air; and **utilising social media and personal networks** to reach people.

08.04.21 – Involving children, young people, and families in our research

Enabling all children, young people and families to be involved/participate in our research

Panel members recommended that **schools and young childhood education facilities** were integral with which to engage, raise awareness of research and utilise their resources e.g. Wi-Fi and existing relationships with children and parents to access participants and conduct research. **Utilising electronic health record (EHR) data** was supported but the **need for consent** was emphasized. **Parents, families, and siblings as well as young children** should be engaged and involved and **engagement with children should be age appropriate.** Links should be made with **maternity and health visiting teams as well as the third sector**. Children should be **given access to their data** to improve its quality and **health inequalities should also be considered and addressed** in relation to child health.

Importance of personalised medicine for children

With regard to the importance of personalised medicine for children, panel members were generally supportive with one panel member surprised that it was not already taking place for young children. Suggestions were made for future research areas including research into **treatment for newborns** and a **predictive tool to help identify those at risk.** The **importance of long- term outcomes** for children

were emphasized. **Relieving the burden on the NHS and families** both in cost and other ways e.g. psychological impact was considered important as was **personalising care to a child's unmet needs** as well as **taking an integrated care approach** to personalised medicine.

Areas of focus across Themes

Panel members considered that **obesity** was common and should be addressed. The **importance of prevention** was discussed and the **need to recognise that there are a variety of causes for disease** including environmental, social, genetic, and also potentially human error. **Rare and more common diseases (e.g. infections, asthma/allergy/pre-school wheeze) were considered to need equal focus**

08.09.21 – Multimorbidity

What are North West London's highest priority disease clusters?

Panel members were very supportive of research into **clusters of disease linked to mental health** as well as finding **biomarkers for mental health**. Other clusters identified as priorities were **diabetes and cardiovascular diseases, allergies, immunology and the mechanisms of autoimmune diseases**. **Frailty** as well as **inflammation** were identified as priority areas. There was wide support for **addressing the treatment of one condition or its side effects then causing another condition** e.g. medication for heart disease leading to kidney failure. The need to look at **intersectionality** around sexuality, religion, socioeconomic status etc was considered a priority and not just looking at people in different silos e.g. men or women. **Health inequalities and inequity** was also considered a priority to include the specific protected characteristics covered by The Equality Act 2010. **Lifestyle factors** were considered relevant including those which did not necessarily link to socio-economic status. Links between **obesity and deprivation**, and **obesity and high BMI generally underlying many conditions. Environmental aspects** which for example, cause allergy symptoms were also considered to be very relevant especially in London. It was also **recommended that a wider priority setting exercise be undertaken across North West London** e.g. a James Lind Alliance priority setting exercise to find out from a larger number of people within the community what their research priorities are.

What are the top patient experience priorities?

The Panel agreed that **communication between healthcare professionals was paramount** and that improved sharing of information and communication between healthcare professionals and between different departments **would improve patient experience.** This was also reflected in a recent James Lind Alliance Priority Setting Partnership on multimorbidity. **Linking up patients with the same conditions was seen as beneficial to patients** so they could meet others like them**. The use of "multimorbidity or co-morbidity" was not considered to be easily understood** by lay people and that using "more than one long term condition" was preferable and easier to understand. Plain language more generally was considered essential e.g. the meaning of primary and secondary care are not easily understood. **Quality of life** and **quality of death** (especially for family members) were also considered to be priorities for those with multimorbidities. **Timing of appointments** was also relevant for patient experience e.g. elderly people can't use their travel cards early in the morning and no one with a condition would want to travel to an appointment during rush hour on public transport.

How can we best involve the NWL community throughout our research process?

Panel members suggested **utilising existing connections with the White City community** through Priya Pallan in the Societal Engagement Team to involve different groups of the community.

Other comments

Panel members were **enthusiastic about, and supportive of, the Theme's research plans** and made some further recommendations to the Theme including: **utilising both qualitative and quantitative research to** add strength to the discussion; **utilising GPs to undertake surveys** about those with co-morbidities if possible, **utilising research from countries which may also be relevant for the North West London population** including India, China as well as Eastern Europe. It was also recommended that the Theme **collaborate with other research** groups undertaking research on multimorbidity to ensure there is no duplication, including with the Applied Research Collaborative (ARC) North West London which also has a mental health Theme.

07.07.21 - Digital Health

Attendees of the discussion session on 7 July 2021, provided helpful insights about **how digital health could improve clinical care, the health of the community and research** especially in relation to **reducing the current fragmentation of data** across the health system. It was suggested this fragmentation could be aided by the **development of easy- to- use patient portals/apps and undertaking of remote monitoring** where patients and their families could record their own health data, access test results and scans, correct data where necessary and receive reminders to aid decision making and self- management. **Identification and understanding of community health needs** could be aided by identifying trends and local services requirements through digital health. **Addressing health inequalities** could involve digitally measuring environmental factors. Using digital tools could assist with **prevention of health conditions** as well as to **address sensitive subjects** including mental health.

However, it was noted that **a hybrid model of care** comprising face-to-face and digital health was needed to: ensure those affected by digital poverty and lack of technical knowledge were not excluded; and for situations where face-to-face assessment is more appropriate and preferable for patients. **Education** about using digital tools is necessary as is **consent,** the **ability to opt out** and provision of **assurance to the public about the security of their health data** which is a continuing concern.

Suggestions to **reduce the digital divide** focused on **ensuring underrepresented communities have access to digital health tools** including the translation of apps into different languages and utilising community leaders and groups to engage these communities appropriately. **Reducing health and social inequalities, making digital tools accessible and easy to use**, providing **education and IT support** to use digital tools and **evidencing their benefit** is also needed to reduce the digital divide.

Suggestions for **how to engage with patients about digital health** included **utilising different ways to engage both face-to-face and online,** utilising **trusted relationships** in primary and community care, **co-designing patient-centric tools and research**, **focusing on the benefits** of digital health and **reassuring the public about data security** were also suggested.

Poll on areas on which digital health should focus

A mid-session multi-choice poll of attendees (n=24/25) revealed that "Understanding disease", "Improving diagnosis" and "Treatment and prevention" all received equal numbers of responses (n=15) to the question: **"On which areas do you think we should focus our digital health research to improve health and care? Please choose your top 3."** The next most popular response chosen was "Individualised care (personalised medicine)" (n=13).

- Understanding disease (n = 15; 63%)
- Improving diagnosis (n = 15; 63%)
- Treatment and prevention (n = 15; 63%)
- Individualised care (personalised medicine) (n = 13; 54%)

Attendees of the discussion session on 21 July 2021, provided their perspectives about real world evidence studies which were broadly centred around both the benefits of, and concerns about these kinds of studies.

Benefits

Attendees considered the benefits of real world evidence studies to include **their advantage over clinical trials,** including the potential speed of real world evidence studies and their ability to **provide additional evidence to clinical trials**. The fact that these studies are u**tilizing an existing data resource** and provide the opportunity to include **wider representation of the population in studies** e.g. pregnant women, disabled people, older and younger people were also identified as benefits. Attendees highlighted the benefit of real world evidence studies **for rare disease and other research** which may not usually benefit from adequate research and/or funding.   Real world evidence studies were seen as also being beneficial **to address health inequalities and social issues** through using relevant data collected in a healthcare setting e.g. infections caused by damp houses, as well as for research areas like **dementia** which impact many people

These benefits were **subject to certain things being put in place or being done** including proper **anonymisation of data, appropriate communication** about real world evidence studies**, use of other recognised data sources** and the **requirement for data quality guidelines**. Attendees also noted that there was a need to be **transparent** about what data is used for and the need for **consent to use real world evidence in studies** including restricting third party access **without consent.**

Many attendees had an **expectation that real world evidence was already being used for** studies and should be.

Concerns

Attendees expressed some concerns about real world evidence studies: **lack of understanding** by the public about what real world evidence studies are**,** the **quality of the data and type of information** used in these studies, a lack of **trust in research,** the **use of anonymised real world data by private companies** and the **financial gain from the sale of real world data by the NHS** which does not filter back to patients to whom the data belongs.

Engagement about Real World Evidence

Attendees also suggested ways in which the public could be engaged about real world evidence studies including **using multiple different channels,** including establishing relationships with **diverse communities** and using **different methods of engagement** including using face-to-face meetings and interpreters. It was suggested that there is a need to **build trust and confidence in healthcare and science in diverse communities** especially since COVID. **Simplifying the definition** of real-world evidence, as well as **simplifying the messages about it and language** would ensure understanding by the general public**, addressing recent negative publicity about the use of patient data, being transparent** about what the data will be used for**, sharing information in accessible formats** including infographics and on social media, and **evidencing the benefits** of using real world evidence in research including using anecdotes about real people and the impact**.**

A mid-session multi-choice poll of attendees (n=22/26) asked the following 2 questions

1. *What areas of research do you think routinely collected health data (as real world evidence) should be used for? Choose your top 3.*
2. *Which of the following benefits of using real world evidence for research are the most important to you? Please choose your top 2*

Responses to poll question 1: "**What areas of research do you think routinely collected health data (as real world evidence) should be used for? Choose your top 3**" were as follows:

64% (14/22) Cancer

50% (11/22) Mental health

36% (8/22)   Heart disease

32% (7/22)   Child health

32% (7/22)   Dementia

27% (6/22)   Respiratory

27% (6/22)   Diabetes

27% (6/22)   Care of the elderly

0%   Other (please write in the chat if you are happy to)

Responses to poll question 2: "**Which of the following benefits of using real world evidence for research are the most important to you? Please choose your top 2**" were as follows:

77% (17/22) Real world evidence includes data from people from diverse backgrounds who would not usually take part in a clinical trial

55% (12/22) Real world evidence includes data from groups in the community which are excluded from clinical trials e.g. pregnant women or those with multiple conditions (co-morbidities)

32% (7/22)   Getting answers to research questions faster than through a clinical trial

14% (3/22)   Research that costs the taxpayer less

0%   Other (please write in chat if you are happy to)

Attendees of the discussion session on 4 August 2021, provided perspectives about both the benefits of using artificial intelligence within their health record to identify possible health risks as well as concerns.

Benefits

The benefits included the **ability to identify potential health risks** especially in relation to genetic conditions within families. They also considered its ability to **improve resourcing in healthcare** (ie. rare blood types) and to **improve healthcare more generally** e.g. for rare diseases and prevention to also be benefits.

Qualifications

The benefits of using artificial intelligence within their health record to identify possible health risks were considered to be subject to certain things being put in place or existing including their **consent** to use artificial intelligence within their health record in this way, the need for the **results to be accurate**, the need for transparency about **artificial intelligence** being used in this way, **medical professionals having the confidence and skill of to use** artificial intelligence and the need for artificial intelligence **to be used as a tool rather than to make a final decision.**

Concerns

Attendees expressed the following concerns about using artificial intelligence within their health record to identify possible health risks: **lack of trust and understanding** of artificial intelligence, the **limitations in communicating about** artificial intelligence to diverse communities**, the **negative reputation of** artificial intelligence from other contexts e.g. school exam results and the **quality/quantity of the data** used in the artificial intelligence e.g. the fact that medical records are not always correct. Other concerns were the **relationship between healthcare professionals and** artificial intelligence not being clear i.e. does it benefit both doctor and patient, **data security and confidentiality** e.g. what if the data is used against you or is released through error, the need to **retain a relationship with the healthcare professional** especially to discuss results identified by artificial intelligence**. The **consequential burden on the NHS** from what is identified by artificial intelligence and **too much reliance by doctors** on artificial intelligence was also seen as a concern e.g. will the doctors default to just using artificial intelligence.

Explanations for poll responses

Attendees provided more details about the reasons for their responses to the poll question: "Which of the following areas do you think would benefit most from the use of Artificial Intelligence and should be prioritised by the Digital Health Theme? (Please choose your top 3)."

Monitoring responses to treatments: to stop treatments that are causing more problems or harm, this presents is a lot of benefit and potential and the fact this is a logical/measurable task which can be delegated to a non- sentient function.

Identifying at risk patients: the doctor would need to confirm the patient was at risk after identification by artificial intelligence. This would assist with prevention and encourage a healthier

lifestyle. It is a logical/measurable task which can be delegated to a non- sentient function and digital tech is less likely to mess up and exacerbate an illness.

Improving patient experience: making artificial intelligence accessible to all especially by using simple language, rectifying a bad experience through use of artificial intelligence, using artificial intelligence to learn patient availability for appointments and improving the patient experience would mean patients are more inclined to seek help early on (and improve outcomes) and digital tech is less likely to mess up and exacerbate an illness.

Assisting with clinical decision making: to be used as a support tool only by healthcare professionals and used properly and responsibly. The large amount of data available means it can be used extensively and it may encourage the doctor to explore certain diagnostics or treatment pathways which may not have been done otherwise and help reduce human error. However, it was noted there is a risk of depersonalising medicine or diminishing the patient/doctor relationship. It was also seen as a logical/measurable task which can be delegated to a non- sentient function.

Monitoring responses to treatments: to be used as a support tool only by healthcare professionals.

Artificial intelligence was seen as good for yes or no answers but that it depended very much on the algorithm to get reasoned answers.

Challenges with artificial intelligence in everyday use

Attendees identified the following challenges with artificial intelligence in everyday use: **lack of accessibility to digital devices and Wi-Fi to access** artificial intelligence**,** the fact that **voice recognition does not always pick up accents** and the **risk of racial profiling.** Another challenge was that artificial intelligence **has been incorrect** as it doesn't always understand what is meant, suggest things accurately and changes choices.

Other comments made to this question were **the lack of understanding of artificial intelligence** in the population including underrepresented communities, the need to **engage the older population** about artificial intelligence and the risk of **hacking and ransom attacks** being a concern in light of recent examples e.g., the Irish HSE.

Poll

A mid-session multi-choice poll of attendees (n=17/19) asked the following multi-choice question:

Which of the following areas do you think would benefit most from the use of Artificial Intelligence and should be prioritised by the Digital Health Theme? (Please choose your top 3)

- Identifying at risk patients
- To diagnose new conditions
- Assisting with clinical decision making
- Helping with providing the best care pathways
- Monitoring responses to treatments
- Improving patient experience
- Other (Please share in chat)

The poll responses were as follows:

Monitoring responses to treatments	76% (13/17
Identifying at risk patients	59% (10/17)
Improving patient experience	53% (9/17)
To diagnose new conditions	35% (6/17)
Assisting with clinical decision making	35% (6/17)
Helping with providing the best care pathways	35% (6/17)
Other	6% (1/17)

29.07.21 – Using the Wynn Database for Metabolic Research

Overall, attendees were accepting of the use of unconsented data within the Wynn Database for further research. Attendees noted that a dataset such as the Wynn Database '**doesn't come around too often**' and felt that it could '**potentially cause harm not to use it**' and highlighted its potential to **improve patient quality of life**, **advance science and understanding of disease**, and increase **opportunity for collaboration**. However, critical to proceeding with its use was the need for the research being undertaken to have clear **patient and public benefit, for the database to be secure, for the data to be properly anonymised and have restricted access, or for a consent process to be in place for third parties.**

However, attendees also noted concerns relating to the potential for **unintentional harm due to lack of consent** and how **generalisable research findings from the Wynn Database may be for current and future patients as tests, measurements and treatments may not now be relevant.**

Attendees agreed that further involvement of patients and the public would be necessary to **minimise unintentional harm**, to **ensure research being undertaken was for patient and public benefit**, to provide **ongoing review as to the ethical appropriateness** of research and to **inform decision making and consent processes relating to the Wynn Database**. Key to these aspects was ensuring that patients and the public were **involved meaningfully, provided with adequate support and those involved represented diverse groups.**

Reflecting on how the Wynn Database team should communicate and engage further with patients and the public, it was suggested that **feedback should be provided at all stages** from updating, linking, and using the Wynn Database to feeding back any research findings and should be **shared across multiple channels**. Some attendees who had taken part in research previously noted the **frustration of not receiving any feedback as to the findings of the study** they had been involved in and also being unable to find relevant publications relating to the research following participation. Efforts should also be made to **reach under-represented groups** and **those who would benefit most from the potential findings** from the Wynn Database.

Attendees of the discussion session on 1 September 2021, provided perspectives about the following main areas.

Taking part in research based on their risk scores from social, genetic and environmental data, to offer "personalised" interventions

Attendees were **broadly supportive** of the potential to take part in studies about social, genetic and environmental determinants of health to offer them "personalised" interventions with one attending commenting that it was **important for there not to be duplication of time and effort and for there to be a tangible benefit and one saying this was particular important for at risk groups in the population**. Attendees considered their participation to be conditional on being provided with **sufficient information** including: **information about data security** (who would have access to the data (especially in light of the recent NHS Digital and GDPR issue) and ensuring Caldicott principles were adhered to so there were no surprises as to where the data ended up); **information about the research** including what the risk factors were, what the treatments/medicines were and risks associated with them , how would the intervention be personalised to them, how would they be contacted and by whom the **time commitment required,** what if they wished to withdraw part way through, what **support, follow up and feedback** would be received and what if **something additional** was discovered to be wrong with them. **Honesty and transparency** about the research was also a requirement. The information provided needs to be **easy to understand but comprehensive**. Some attendees were not keen to take part in a trial of an **investigational drug** unless it was safe and had been tested.

Being reminded before being contacted again to be invited back to take part in additional research

Attendees were overall supportive of having more frequent communication. One attendee suggested **using automated notifications to update and keep in contact with people** and **to keep in contact even if nothing is happening** and in order that when people are contacted it is **not out of the blue. Reminders are also helpful.**
Who do you think should contact you, and how?

In terms of by whom people would like to be contacted about this research, attendees who were currently part of a research register expressed that they would be happy to be contacted by the **register** or **by Imperial College,** having provided their consent to be contacted about future research. Another said by researchers or practitioners. Other suggestions for inviting wider participation in future research included utilizing **existing trusted contacts, networks, patient groups e.g. Heartlink** (heart patient group) and **GPs** (if possible) although one attendee considered GPs were not where she expected to hear about research. It was also considered important to **involve local communities from diverse backgrounds** in the research. One said that if it is **personalised based on a risk score** then it would be useful to be contacted with more information with a knowledgeable person to call.

One attendee stated that people would **need to be confident in the legitimacy** of the contact (i.e. was it a genuine research study or a scam). Communications also needed to be **made appropriate to the recipient** e.g. an elderly person may not want an email or someone may not be illiterate. One attendee considered that a personal approach (e.g. by contacting someone's family members who may also be at risk) should be adopted to invite people to take part in this research.

Responses to increased genetic risk of a disease

Although receipt of information about having an increased genetic risk of a disease was considered by some to be considered to be a benefit. One attendee was apprehensive about finding out this information and one was unsure as to how they would feel until faced with it. There was acknowledgement of it also potentially being **frightening** for people. Attendees recommended that **communicating this information should be done sensitively and in person** or **over the phone rather than in writing** by letter or email and **at a time when the recipient chooses**. It would be beneficial if it was communicated **by someone they knew** who could explain how it was discovered and the **next steps.** Attendees considered that **support would need to be provided** to offer people coping strategies including **talking therapies**.

Would it change your relationships with family, or health professionals?

There was a mixture of responses as to whether knowledge of such a risk would change relationships with family members as it may impact someone negatively if the risk was as a result of a genetic issue. It may also depend on a person's culture. One said it would enable them to be closer to both their family and health professionals. Two attendees were unsure if they would share the information with family members. One wasn't sure if their relationship with family and health professionals would change and one didn't think so. One said their relationship with health professionals wouldn't change. It was noted that the knowledge of having an increased genetic risk of a disease could also have an impact on one's **relationship with an employer**.

Perspectives on proposed research programmes (i.e. prevention, COVID-19 recovery, adolescent health, dementia)?

Attendees were broadly supportive of the proposed research areas as these are currently prominent areas. **Prevention** was considered to always be better than cure albeit a wide parameter, to be less costly and more effective than having to come up with a solution and reduces strain on the NHS e.g. diabetes. **Adolescent health** was considered important by identifying issues at an early stage although the age needed clarification.

Attendees also made suggestions for additional programmes of research including **diabetes** and in particular**, adolescent diabetes**, **mental health** (and the impact of people returning to a post pandemic normality after being "institutionalised" by lockdown) and the **impact of COVID 19 on child development**. Research on the **learnings from COVID 19** were also suggested i.e. the positive outcomes which could be applied more widely e.g. mask wearing to avoid winter infections, successful vaccination programmes. Additionally, **respiratory illnesses** research was suggested especially in relation to those with pre-existing health conditions e.g. asthma in light of the impact COVID 19 had on asthma patients. One attendee considered the proposed programmes to be **ambitious and broad** and another considered the programmes to be overlapping e.g. COVID -19 recovery and alcohol use and abuse during the pandemic. The precision medicine aspect was considered to be **"ground-breaking"** by one. Attendees considered there was a **need to address digital exclusion and digital poverty** which if technology was to be used in the Theme's research (which was supported) would exclude people. To overcome this, **partnerships with voluntary and community sectors** would be required**.** It was noted that some people have a **disinterest in using technology, even** if they have access to it. Attendees considered the Theme had the **unique opportunity to dispel myths about certain conditions** e.g. that type 1 diabetes is caused by bad diet or too much sugar and all liver disease is caused by alcohol abuse. There is also an **opportunity to educate** patients about their own conditions with provision of more information than is currently available (e.g. for Type 1 diabetes by the NHS) and to also educate the public more broadly to

address the apportionment of blame to individuals who have certain conditions which are caused by genetics. Patient groups could be utilised to help educate and raise awareness too.

02.09.21 – Metabolic medicine – weight and fertility

Attendees of the discussion session on 2 September 2021, provided perspectives about the following main areas.

Views on the research area

Overall attendees were supportive of the proposed research area and recognised the importance of this research to help increase understanding of the complex topic of weight and fertility which could also in turn empower patients to make more informed decisions about fertility treatments.

Concern was raised about both research and clinical practice focusing on weight as the cause (or main factor) of infertility, noting that 'not all overweight people have a problem getting pregnant' and that it is not the only factor to be considered when looking at infertility and other co-morbidities (e.g., high blood pressure, gestational diabetes), with each individual having their own personalised risk of health outcomes based on both physiological and psychological factors.

Attendees also raised concern around the limited options for fertility treatment in clinical practice, and the parameters around accessing these which are currently focused on age and weight-related metrics (body mass index) to decide who gets to access treatment, rather than other important health outcomes (such as amount of exercise, nutrition, and other lifestyle factors).

Views on other factors which required consideration

Attendees considered that a number of other factors should be considered when undertaking this research to increase understanding of this complex area The **impact of weight (and infertility) on mental and psychological health** was identified as extremely important. The **role of cultural facto**rs was also raised, as for some cultures, weight can be seen as a sign of 'wealth and power', and also how infertility is perceived across different cultures. Other areas for further exploration included **understanding further who would benefit from fertility services**, **understanding physiological and psychological factors which play a role in weight-gain, weight-loss, and fertility**. Research into **Polycystic Ovary Syndrome (PCOS), Type 2 Diabetes, eating disorders**, and the **impact of health promotion behaviours vs the impact of weight loss** were also suggested.

For some, other areas of health were raised as important areas to explore further in relation to weight. These included cardiovascular issues, diabetes, cancer, and gestational diabetes. Others, however, highlighted that they were more concerned with completing daily tasks and activities than wider health outcomes, noting that weight only minimally increased the risk of such outcomes.

Education and awareness around health and fertility was considered important, to empower people to engage with their health and to access support and treatment. Linked to this, attendees felt there was a **need for better access to clear and understandable information** and **evidence about this topic, particularly for under-represented communities**. It was also considered **critical that there was greater awareness around stigmatisation linked to weight.**

Views on weight and/or fertility interventions and treatment

When discussing access to support and treatment for weight and fertility, attendees suggested that such clinics and interventions should: be **specific and personalised** to each individual, **include referral**

to or provision of support services such as mental health or nutrition support**,** provide **increased mental health support** when navigating weight and fertility services and throughout treatment and pregnancy, be **person-centred which look at the problem holistically,** including any underlying **factors** (both physiological and psychological) which could be contributing to infertility**,** and **give patients a choice and a voice** in their treatment.

While some felt that these interventions should be initiated by their GP, others felt that this would only be appropriate if the patient had a personal or established relationship with their doctor.

Views on communicating with patients and the public about weight and fertility

When communicating about health risks, attendees felt that it was critical **'not to always assume that weight is the issue'** and **wanted researchers and clinicians to take a more balanced view on risk**, with attendees noting **the harm which negative messaging around risk may cause to people**. This included **recognising people as individuals** and not 'lumping people with high BMI all into one category'.

When communicating about weight, attendees felt that **weight-related terms should not be the only terms used**, as 'some individuals may not recognise themselves as obese, overweight, or having a high-BMI'. Attendees suggested that focusing more on blood pressure and other aspects of physiology may be a better 'tactic'. **Asking patients for their preferred terms** was suggested, as it is unlikely that there would be 'one term for everybody'. It was cautioned that **stigmatising language which passed blame and made assumptions around food and exercise should never be used** and that **providing further context to support any language or terminology used** would be helpful.

06.09.21 – Metabolic Medicine – Non-Alcoholic Fatty Liver Disease (NAFLD)

Overall attendees were supportive of the two research areas explored during the session: improving diagnosis of NAFLD through Artificial Intelligence and improving treatment of NAFLD through hormones. Attendees were **supportive of the development of a single non-invasive diagnostic test** to improve diagnosis of NAFLD and noted that the use of artificial intelligence to support this development could, **save time**, **enable earlier diagnosis**, and **could help researcher to learn more about the disease** if implemented more widely, including internationally. When discussing the acceptability of this method, some individuals raised **concerns over the quality of data being inputted** and the **potential accuracy of the programme**. Some felt that **the benefits outweighed the concerns** and that **clear explanation of the role of AI could help alleviate concerns**.

Attendees also provided views on the research into hormonal treatment of NAFLD and the perceived acceptability of using a hormone pump as a means to deliver the treatment. Overall, attendees felt that **wearing and using a pump was a minimal inconvenience in relation to the benefit of a possible treatment for NAFLD**. Some individuals wanted **further information about the pump**, including whether it was painful, what it looked like and how long it needed to be worn for and another felt that **where the pump was placed needed further consideration** to maximise comfort for individuals.

In addition to the research areas discussed, individuals also suggested further areas of focus which the researchers should consider, including **more work on prevention**, **exploring the role of genetics and ethnicity on diagnosis**, **development of screening programmes for NAFLD** and **exploration of other contributing factors including gut health, diet, and weight**. Alongside the research, individuals also felt that **promoting liver health** and **further education for the public about the liver and NAFLD** where needed.

When asked about public engagement and involvement in NAFLD research, attendees felt that it was first **critical to raise awareness of the seriousness NAFLD**, as well as **promoting ways to achieve good liver health**. Individuals suggested that creating a **media campaign** and **advertising through different mediums,** such as social media, television, and flyers in GP surgeries, as well as **advertising in a variety of languages** would be helpful ways to **increase awareness and education about this disease**. When reflecting on motivators and barriers to participating in NAFLD research themselves, **losing weight and improving health** was felt to be a motivator, whereas concerns around **possible adverse outcomes from clinical trials**, **the impact of using hormones** and **maintaining outcomes after the trial** were cited as barriers. One individual also highlighted the issue that many ind**ividuals are unaware that they are at risk of, or have, NAFLD** which would hinder recruitment.

14.09.21 – Molecular Phenomics

Attendees of the discussion session on 14 September 2021, provided the following perspectives:

Overall attendees were supportive of the use of molecular phenomics to improve clinical care, personalised medicine, and community health with individuals noting that it is an 'interesting topic which everyone should be aware of' and the area was 'important to open a new frontier in treating disease'.

During the breakout room discussions attendees were posed three possible scenarios in which molecular phenomics could be used in the future. Their reflections are captured under the following questions:

Which scenario would you prefer, if any, and why?

A toilet in your home that can provide feedback about any aspect of your health through automated urine analysis: This scenario was considered **convenient** and was noted to save time and effort compared with having to go to the GP or walk-in clinic to undertake such a test. **Reducing burden on GPs** and the NHS was cited as a reason for this possible scenario to be preferred, as well **as being able to get results quickly** and having **greater responsibility over health** including the **ability to self-monitor and manage health**.

Concerns for this scenario were raised around **intrusiveness, accessibility** (if there was a cost implication) and most significantly the potential for having such a tool available in your own home to **cause anxiety or have a negative psychological impact**.

Providing reassurance, having the opportunity to **obtain professional interpretation of results**, and **doctors monitoring and screening feedback before it goes to the individual** were considered important**.** It was also felt that any information or feedback provided should be **accompanied with further support and advice**.

A walk-in clinic, [separate from your GP and open to all] that conducts urine tests to analyse any aspect of your health: Comments in support of the walk-in clinic scenario cited it as being **less intrusive** (compared to the first scenario) and enabling you to have **greater autonomy** over what you want to do. Being **separate from the GP** was also considered preferrable, as well as potentially being **more accessible** for people.

A urine test, conducted by your GP, which can be sent off to analyse any aspect of your health: Comments in support of having a test at the GP, noted that this was preferred as you already have an

existing relationship with your GP and that this felt **more professiona**l. Attendees also felt that it was beneficial to be able to **follow-up or ask questions** following the test results.

Across scenarios, concerns around **accuracy** of such tests and **mistrust of results** were raised, alongside potential **issues with data sharing and security** (i.e. where the information goes and how it will be used) and **implications on insurance** if knowledge about your own health was more readily available.

What sort of information about your health would you want to know?

When asked about the type of information that they would like to find out about their health, responses were varied some attendees wished to **know everything (the good and the bad)**, which was **very detailed and comprehensive.**

Information about **early identification of disease or illness**, including information which would help **prevent and lower risk of disease** were considered important. Information on **medication responses**, **hormone imbalances**, **nutrition and diet**, and the **impact of environmental factors on health** were also highlighted. While some attendees were keen **to know their risk or genetic predisposition of having a disease,** others felt that they wo**uld not want to know while they were still young** and **if there was no cure/treatment available** for the particular disease. For attendees who did not want to know about risk of disease, it was considered acceptable for such results to be directed to a GP, or other health professional.

Further, it was considered important that any information or feedback received about health should consider the potential **psychological impact of receiving such information** and that **additional support and advice should be available** or provided. It was also suggested that **the type of tests undertaken should be the choice of the individual** and mechanisms should be in place to choose personalised options, flexibly.

How would you like to receive information about your health?

Views on the frequency and mode of delivery of information about health were varied, some individuals wanted **information as soon as possible**, while others felt that **being able to delay when information was received** may be beneficial. Many preferred to **receive information face-to-face or in person (via phone or video call)** and wanted **information to be delivered by a professional** (e.g. GP), so they could **follow up and ask any further question**s. Others felt that **sharing information via the NHS app or other smart app** would be preferred.

Overall, the preferred mode of delivery was largely dependent on the seriousness of information with individuals wanting the **information to be delivered in person by a health professional if more serious** while **minor information could be received via text, email, app or phone call**.

A **personalised approach** was again cited as important, with **individuals giving the choice and flexibility to decide how and when they receive information**.

Are there any other ways that you think we can use molecular phenotyping to improve clinical care and the health of our local community?

Early identification of disease and illness such as **diabetes, heart problems, cancer a**nd **lung disease** were considered a priority, as was **identifying other ailments such as intolerances and allergies, pain,** and **depression,** if technology permitted**.** Exploring response to treatment was also considered important, particularly in regard to **new medications**, and **identifying any adverse reactions** following treatment. **Personalised health** was also raised as an important area with individuals wanting to know

what medications suit them best, **what lifestyle changes they should be undertaking to prevent disease**, and to **support nutrition**, **inform pregnancy** and **weight loss**. Using molecular phenomics to; e**xtend research into the areas which 'most people are suffering'**, increase **accessibility to healthcare** and **help manage long-term conditions** were also raised as a priority.

3.3 Feedback from Public Involvement Surveys

Respiratory

A total of 116 responses were received from individuals across the North West London Community who had lived experience of a respiratory condition (as a patient or carer/family member/friend) or had interest in this area of research.

Respondents were asked to share their views on respiratory research priorities by ranking research areas which were perceived to be most important areas to pursue.

Across respondents, '**identifying the causes of lung disease in early life**', '**understanding how pollution impacts the lung**s' and '**developing new treatments for patients with advanced lung disease**', were the top three ranked priorities, with 'exploring safe alternatives to replace cigarettes' considered the lowest priority. Responses from people living with respiratory conditions, placed greater priority on '**finding better ways to avoid and treat patients with flare-ups of their lung condition'** as well as '**understanding how viruses (e.g., COVID-19) damage the airways and lungs**', than other respondents.

Involving children, young people, and families in our research

The responses to the survey represented 74 children from 51 respondents. Respondents were asked to share their views on child health research by ranking research areas which were perceived to be most important for research to pursue across Themes as well as their opinions on possible research methods and their own child/children being invited to take part in research.

In regard to overall research priorities, respondents ranked both **the most common illnesses which cause children to need to go to repeated GP appointments or hospital outpatient appointments over long periods of time** and **rare illnesses which cause a sudden life-threatening problem or cause children to need many hospitalisations** as the most important areas for research to pursue.

When asked about childhood infections, respondents ranked **better ways to find the cause when a child has a suspected infection** as the highest priority**,** followed by **more research into developing new vaccines to prevent common childhood infections.** For research aiming to develop new tests to identify suspected infection within children, respondents felt that an **accurate test (that will almost always be right) which may take longer**, was more important than a **quick test with less accuracy.**

Research into **developing new tests for childhood wheeze** should be prioritised as well as **identifying the cause of the problem** and **finding the best treatment.**

Respondents' rankings identified that following a period of serious illness for a child which required a long hospital stay, research should be focused on **preventing it from happening again,** followed by **understanding why it happened.** Genetic testing to identify a possible genetic cause of a serious illness was considered appropriate with the majority of respondents wanting to know any **relevant results from genetic testing related to the child's illness as well as any other results which may be significant (e.g. to other family members')**

Respondents were also invited to share their views on the use of routine data for child health research. When data was de-identified, respondents felt an opt-out process **for people to be able to say if they don't want their data to be used in this way for research** was most important, in

comparison to data where individual children may be identified, in which an opt-in process with **people specifically being asked to agree for their data to be used in this way for each research project** was preferred. Additionally, respondents were less in favour of **'data being easily available for research' when** there was a chance that individual children may be identified.

Lastly, respondents were asked to provide their views on whether they would be happy for their child to hear about opportunities to take part in research from a relevant health professional while at hospital. Overall, respondents were happy for this to happen, but i would like **to know more details about the research.**

Molecular Phenomics

In total, 1023 responses were received from individuals across the UK using the online survey platform (Qualtrics). Individuals were invited to complete the survey if they had received a missed, late, or incorrect diagnosis.

A preliminary analysis was conducted which considered only respondents who had reported receiving a clear and accurate final diagnosis after a period of one or more years of misdiagnosis (n=319; broken down in the figure below), representing the most severe (in terms of both personal and healthcare system-related impact) cases polled:
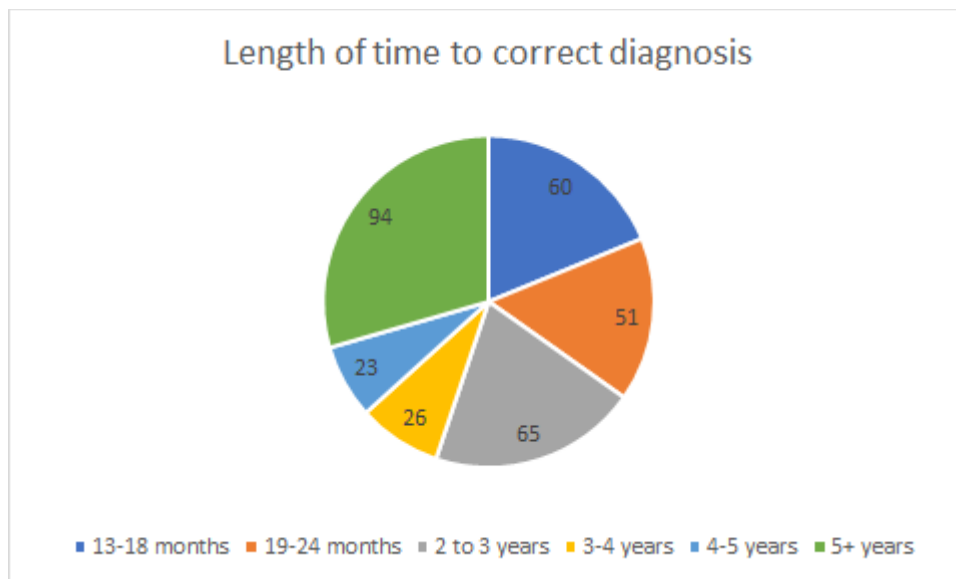
The data reveals previously unseen insight into both diseases which are difficult to accurately diagnose and diseases that masquerade as others, resulting in misdiagnoses and mistreatment. A more comprehensive analysis is ongoing, however, the following diseases were of initial interest due to their frequent reporting:

- Cancer was the most widely reported final diagnosis (n=19), including bowel, bladder, kidney, prostate, cervix, skin and breast.
- Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) was reported seven times, mistaken for depression.
- Rheumatoid Arthritis was reported seven times, mistaken for wear & tear, bone fractures and Raynaud's.

- Parkinson's disease was reported 6 times, interestingly with no misdiagnoses in any reported cases, but all cases requiring between 1 and 3 years to diagnose.
- Hiatus hernia was reported 6 times, mistaken for a wide range of conditions including COPD, bowel cancer, IBS, and chronic cough.
- As a pair of interest, chronic obstructive pulmonary disease (COPD) was reported 5 times, mistaken for asthma. Whereas asthma was reported 6 times with 5 of 6 patients reporting more than 2 years. It is important to note that the treatment for these diseases is different, with asthma requiring suppression of chronic inflammation and COPD requiring management of symptoms.
- Fibromyalgia was reported 5 times.
- Hyperthyroidism was reported 5 times, most frequently mistaken for depression.
- Adult growth hormone deficiency was reported twice, both times with time to accurate diagnosis exceeding 5 years. It was mistaken for mental health disorders, malingering, depression, and anxiety.
- Bipolar disorder was reported 5 times, mistaken for depression, anxiety, schizophrenia. 5/5 patients reported at least 3 years to diagnosis.
- Bronchiectasis was reported 5 times, generally mistaken for asthma, acid reflux, lung infection or viral illness.
- Endometriosis was reported 4 times, most frequently mistaken for IBS. Crohn's was reported 3 times, also mistaken for IBS (as well as lactose intolerance). Chronic pancreatitis and Coeliac were both mistaken for IBS. Both bowel and ovarian cancer were misdiagnosed as IBS. Interestingly, IBS, in the absence of hiatus hernia, was not reported.

The above preliminary findings identify the need for improved disease stratification (classification into different groups), specifically where symptom reporting may be general (e.g. where many distinct diseases appear to be mistaken for IBD). Further, the heterogeneity (diversity) in undiagnosed diseases (with the majority of reports appearing as single cases in the collated data) represents a substantial challenge for accurate disease diagnosis and future treatment. Powerful metabolic phenotyping technologies are ready to be able to assist here, if the field can be moved onward from exploring the metabolic underpinnings of single diseases (vs. healthy controls) to looking across diseases that are prone to misdiagnosis or that fall under the umbrella of a single symptom set.