Eating Disorders Research Workshop
27th - 28th June 2022
Report

Contents

1. Background

UK Research and Innovation through the Medical Research Council (MRC) and Economic and Social Research Council (ESRC), along with the Medical Research Foundation (MRF), National Institute for Health and Care Research (NIHR) and The UK's Eating Disorder Charity – Beat convened a Workshop to identify research needs and opportunities in the area of Eating Disorders (ED).

MRC and MRF have previously led two funding calls to support research in ED and self-harm. Additionally, NIHR has funded Eating Disorders Genetics Initiative UK along with a wide range of research into clinical aspects of ED. To build on these strategic initiatives, and other investments in ED research made by the funders, and considering the findings from the recent All Party Parliamentary Group inquiry into ED research in the UK, the workshop brought together key stakeholders to identify areas to further progress ED research.

2. Purpose

This workshop aimed to identify gaps in current ED research, priority questions and opportunities for future ED research and to understand how to facilitate stronger dialogue and collaborations with other related areas of research (e.g. conditions that are comorbid, or share common features/behaviours, with ED). The workshop therefore brought together a variety of invited experts with interest in this area.

Five key areas were addressed:

- mechanisms
- career progression
- Patient and Public Involvement and Engagement (PPIE),
- data
- treatment

The topics were introduced by speakers followed by structured discussions in breakout rooms. To ensure depth of discussion, breakout room participants were asked to consider the questions from different viewpoints in light of their own area of expertise. The breakout discussions were then summarised to the Workshop participants in a plenary session.

This report aims to summarise the key points of discussions, findings and recommendations from the workshop.

3. Speakers

3.1 Psychological mechanisms of ED and co-morbidities – Professor Fernando Fernández-Aranda

Professor Fernández-Aranda discussed the evolution that has taken place in ED research, moving away from the view of ED as a solely psychological issue and highlighting the important contribution of biological and social factors. The following points of interest were highlighted:

- The Covid-19 pandemic has exacerbated the risk-factors for ED.
- A number of biological and environmental factors are shared across ED and co-morbid disorders such as obesity, behavioural addictions and impulse-control disorder.

In addition, a number of key challenges for the next decade in the management of ED were highlighted:

- Effective management strategies and how to deal with drop-outs.
- Chronicity and aging in ED.
- Personality traits and comorbidities.
- Robust neurobiological and metabolic markers and risk factors.
- Lifetime obesity and ED.
- To establish personalised approaches and optimise care pathways.

3.2 Neurophysiology of ED – Professor Guido Frank

Professor Frank discussed how neuroimaging has shed light on the mechanisms of ED and the specific involvement of different brain regions in motivations of food control and intake. The following points of interest were highlighted:

- Over- /under-eating changes brain circuitry [e.g. DA] and presumably ED-relevant behaviours.
- Brain circuits have been associated with behaviours such as reward processing, impulse control, conditioning, fear circuitry.
- We can draw from other psychiatric research (mood, OCD, psychotic disorders) and apply to ED research.
- We have neuroscience frameworks to explain interactions between traits, learning and behaviour development and modification.

He also outlined a number of opportunities for future research:

- How ED behaviours link to brain activation results.
- How neurotransmitters affect brain activation and ED behaviours.
- Relevance of brain alterations during underweight that recover with weight restoration.
- EDs brain imaging studies focused on developing transdiagnostic models.
- How ARFID relates neurobiologically to "Classic EDs".

3.3 Biological mechanisms of ED – Professor Johannes Hebebrand

Professor Hebebrand discussed the biological mechanisms of ED and obesity and the possibility for pharmacological interventions. The need to debunk myths in the field that postulates these disorders as either purely biological or purely psychological was emphasised and better integration of multiple perspectives advocated for. Key opportunities areas for research were identified as follows:

- Understand that restrictive eating depends partly on psychological/personality features.
- Understand that restrictive eating entails psychological and behavioural changes.
- Understand the interwovenness of genetic, psychological, environmental and social factors.
- Better integrate psychological and behavioural research.

- Appreciate the importance of body weight and achieve consensus as to its assessment and definition, alternatively substitute underweight with symptoms of starvation for the diagnosis of anorexia nervosa (AN).
- Appreciate the interwovenness of starvation and clinical symptomatology.
- Understand the biological mechanisms involved in the adaptation to starvation including the prominent role of the hormone leptin.
- Test the hypothesis that the reversal of the endocrine adaptation to starvation benefits patients with AN.
- Understand entrapment in anorexia nervosa.
- Appreciate environmental/psychological/social context (e.g. Covid-19 pandemic) while integrating biology

3.4 Sociocultural aspects of ED – Professor Phillippa Diedrichs

Professor Diedrichs discussed how sociocultural factors can constitute important risk factors for development of ED, while also contributing to prevention and presenting opportunities for support. The following gaps in current research were highlighted:

- Research on how risk factors might interact together or with other demographic and social identity factors (e.g., race, class, gender).
- Research has been predominantly conducted with adolescent girls and young adult white women in high income countries immersed in Western cultures.
- Research during mid-life and older adulthood.
- Recent prospective, longitudinal and experimental research on media influence, in particular social media.
- Research on protective factors, in particular positive body image.
- Research on prevention, which can elucidate causal factors.
- Research investigating the impact of sociocultural environments saturated with weight bias and anti-fat attitudes.

She identified a number of resources and research topics needed to move forward in this area:

- Prospective and experimental data to examine causation among mid-life women and men.
- Gender diverse and non-white samples.
- Investigations of the interaction between body image, disordered eating and various social identities.
- Testing of existing models and adapting models to suit different life stages and social identities.
- Use of prevention and intervention studies to identify causation.
- Investigations of the broader sociocultural climate around weight-based prejudice, fat phobia and obesity prevention efforts.
- Examination of protective factors, particularly through the lens of positive body image and embodiment.

3.5 The Current State and Future Opportunities for Patient Public Involvement & Engagement in ED Research – Dr Una Foye and Helen Missen

Dr Foye and Helen Missen discussed how patient and public involvement and engagement (PPIE) has become increasingly incorporated into the research landscape and the need for agreement on best practice, while acknowledging the important role of carers and people with lived experience of ED as support both for patients and researchers. The following points of interest were highlighted:

- The current policy landscape advocates for the involvement of people with lived experience in the co-production of mental health services and involvement in the co-production – whether that is co-design or co-delivery – of any research study, project or intervention empowers those with seldom-heard voices and lived experience to collaborate meaningfully.

- We must acknowledge that co-production is a key principle in the agenda to advance mental health equalities (National Collaborating Centre for Mental Health, 2019) and thus ought to be used to address the inequalities in ED service provision and research.
- Despite this emerging practice, there has been little progress in synthesising best practice in involving people with lived experience in the prevention and treatment of EDs from a research perspective.

They identified a number of key research priorities based on PPIE insights :

- Use lived experience to make research meaningful, to improve outcomes, reduce the impact of ED and to understand what recovery is like from a lived experience perspective.
- Understand why these illnesses happen to some people but not everyone (individual differences, e.g., endocrinology, genetics, socio-economic status, etc.) as well as viewing this from a population level.
- Research to help tackle discrimination and inequalities.
- Person-centred activities as not everyone with an ED is the same.

3.6 Future data collections and measures – Professor Ann John

Professor John described the efforts made to date in gathering and harmonising Mental Health research data through DATAMIND – The Health Data Research Hub for Mental Health. She highlighted the types of resources that are and will be available through the Hub:

- Cohorts.
- Bioresource.
- Electronic Health Record data.
- Administrative data (non-health).
- Other data such as geospatial data and social media trends.

She also highlighted a number of areas where challenges in achieving harmonisation remained:

- Accessibility (in reality, beyond 'discoverable').
- Linkages and networks.
- Data depth and visibility (Natural Language Processing).
- Local/National dichotomy.

3.7 Research gaps in treatment of ED – Professor Janet Treasure

Professor Treasure discussed the current state of treatment for ED and targets for therapeutic intervention. She highlighted a number of key research priorities to advance therapeutic avenues for ED:

- Prevention and early intervention (e.g., EDIFY).
- Social and family support are essential.
- For anorexia nervosa (AN): target eating through adjuncts to psychotherapy such as exposure treatments and neuroplasticity-enhancing interventions (e.g. psychedelics/ (non)-invasive brain stimulation).
- For Bulimia Nervosa (BN) and Binge Eating Disorder (BED): target dysregulated appetite & impulsivity (brain training /stimulation etc).

4. Recommendations for research in Eating Disorders

4.1 Research into Mechanisms of ED

Breakout Groups:

Group 1: Psychological mechanisms, Moderator – Ulrike Schmidt

Group 2: Neurophysiological mechanisms, Moderator – Guido Frank

Group 3: Biological mechanisms, Moderator – Stephen O'Rahilly

Group 4: Sociocultural mechanisms, Moderator – Phillippa Diedrichs

Group 5: Mechanisms of treatment, Moderator – Janet Treasure

Questions posed:

- ❖ Which underpinning mechanistic areas would be best explored to offer the greatest opportunity to strengthen research into ED?
- ❖ What data is missing to allow the field to progress?
- ❖ What are the greatest requirements needed to make progress in the field (e.g partnerships/collaborations/infrastructure/resources/methods)?

The breakout groups discussed the above questions from different perspectives and summarised the top priorities in a joined discussion. Workshop participants made the following recommendations to progress research into mechanisms of ED;

Future mechanistic research areas

- Improve early detection of ED as early intervention has a much better outcome than later stage or delayed treatments.
- Identify and target the maintaining mechanisms in ED.
- Understand the large and specific impact the Covid-19 pandemic has had on ED, taking into account the intersection with socioeconomic factors and ethnicity.
- Explore how genes influence brain structures and processes involved in thinking about eating; investigate how these structures and eating behaviour changes when particular molecules are disrupted.
- Improve understanding of benefits and risks of social media use.
- Conceptualise health biases in society towards weight and their effects on the ED community, particularly in light of recent focus on obesity.
- Prioritise mechanistic understanding of ED using systematic studies.

Interdisciplinarity and comorbidities

- Capitalise on adjacent relevant data from neuro-cognition, anthropology and new media studies to foster trans-disciplinary research outside of psychology/psychiatry.
- Focus on trans-diagnostic mechanisms, such as the relationship between weight, shape, body image and eating, which are relevant for multiple conditions.
- Consider disordered eating, outside of AN, more broadly, including people who might not meet diagnostic criteria.

- Focus on co-morbidities relevant to ED such as anxiety, impulsivity/compulsivity, addiction and attention deficit hyperactivity disorder (ADHD).
- Move beyond individuals and consider public mental health approaches, which necessitate engagement with broader stakeholders including industry.
- Encourage engagement of different research disciplines.

Improved measurements

- Increase range of measurements and improve assessment methods to capture clinically relevant behaviour and improve understanding of brain circuitry involved in ED.
- Bring together relevant stakeholders to compare and contrast measurements and agree on best practice.
- Take a public health approach in modelling and analysing data to inform early intervention.

Cohort data

- Ensure longitudinal, deep-phenotyping datasets capture behavioural data and biological measurements such as imaging, epigenetics, hormonal levels and microbiome composition to link body and brain also across the lifespan.
- Capture risk data through high quality longitudinal studies taking place before onset of ED, ensuring that epidemiological studies are large enough to include low incidence EDs.
- Leverage existing datasets of various sizes and add additional measurements relevant to ED, including:
    o Large scale international datasets, such as the Adolescent Brain Cognitive Development (ABCD) study or national birth studies.
    o Large scale genomic data, including from the private sector.
    o Deeply phenotyped cohorts, such as ALSPAC.
- Input into the development on the upcoming adolescent cohort and ensure inclusion of detailed information on eating behaviour in existing and future cohorts/datasets.
- Improve integration of various types of data and optimise research pipelines for forward and reverse translation from large scale datasets into experimental studies.
- Consider the underlying factors for differences in phenotypes between cohorts.

Animal models

- Conduct in depth behavioural phenotyping relevant to ED in already established models, linking animal to human data given that high detail investigations of mammalian eating behaviour and the availability of genetic tools has increased the range of behaviours that can be studied in animals.
- Include a focus on Binge Eating Disorder (BED), where there might be more tractable targets for treatment than for AN.

Representation in research

- Develop research in collaboration with people with lived experience of ED and carers.
- Broaden research on and awareness of ED in terms of under-represented groups, as there are likely to be different mechanisms for different experiences of and

trajectories into eating disorders. Include a global perspective, consider the LGBTQ+ community, expand the age-range, include men and other underserved groups, and take a transdiagnostic approach.

Mechanisms of treatment

- Consider targeting hormonal deficiencies in ED, as recent findings highlighted a need for randomised controlled trials (RCT) in this area.
- Use neurobiology and neuroimaging to disentangle cause and effect across the diversity and presentation of symptoms in ED in order to individualise treatment approaches.
- Better understanding of effectiveness of inpatient treatment and the role of structure and routine versus psychological skills therein.
- Integration of biologically-based approaches with psychology.
- Consider impact of people with lived experience of ED's perceptions and beliefs about treatment, including the impact of framing in terms of what can be gained rather than just the prospect of taking away existing (albeit unhealthy) coping mechanisms.

4.2 Career progression

Panel:

Jeremy Hall (Chair)

Margaret Westwater

Samuel Chawner

Caitlin Lloyd

Dawn Branley-Bell

Questions posed:

- ❖ What are the barriers to career progression in the field of ED research?
- ❖ How can these barriers be lowered?

The Panel discussed the above questions based on their own experience and perspectives as early-career researchers (ECR) in ED research. The Panel made the following observations and recommendations regarding career progression in ED research;

Research access

- *Access to research participants, data-sets and ongoing studies is challenging for ECRs, who might rely on smaller datasets or secondary data analysis leading to their work being seen as less relevant and competitive. This barrier could be lowered through:*
  - o Increased collaboration across research groups.
  - o Provision of easier access to clinical data and encouraging open science practices that involve the sharing of data and code across different research groups/institutions to increase sample sizes.
  - o Early linkage of ECRs into discussions around future data gathering.

Stigma

- *Despite sizeable media attention, the All-Party Parliamentary Group on ED highlighted that ED research has been under-funded compared to similar health conditions. There is a view of ED as self-inflicted which creates stigma – trivialising these serious conditions. This might lead to ED research being perceived as niche or less important by Research Organisations (RO) resulting in lower priority for applications in this area. This could be alleviated via;*
    o Improved visibility of funding schemes targeted at various career stages; MRF Fellowships were commended as a strong scheme to retain and develop ED researchers.
    o Emphasising the importance of EDs by encouraging greater representation in broader psychiatry/psychology/neuroscience journals and conferences.
    o Active consideration of opportunities for funding in adjacent fields, for instance diabetes research.
    o Creative and innovative initiatives targeted at ECRs through research partnerships and funding calls, e.g the recent MRC neuroimmunology call.

Institutional barriers

- *ECRs often benefit from being part of large research centers, and these are rare in the UK for ED. There is therefore a need to think more carefully about networking support in the community across institutions and research fields.*
- *Many institutions also do not have a well-developed research framework, so ECRs need to spend more time on lecturing than on research.*
- *Technology often moves faster than funding processes, and since ECRs are often at the forefront of technology, this means opportunities could be lost.*
- *Siloed thinking is an issue, and it needs to be highlighted that ED research is interdisciplinary, particularly as ED encompasses both physical and mental health. How to lower these barriers;*
    o Better embed ED researchers into larger centers already focusing on related areas such as other mental health and physiological conditions, e.g obesity and diabetes.
    o Expand infrastructure to support cross-cutting research themes in ROs.
    o Apply bridging funding to enable ECRs to spend more time on research.
    o Active support for ECR networking initiatives through ROs and funders.
    o Previously funded MRF/MRC partnerships should take an active role in networking activities to build on the momentum from their awards.
    o Support the development of more ED research centres/groups in the UK, including by building links between universities and local NHS Trusts/Health Boards.

Limitation of field

- *As a non-clinician it might be difficult to pursue ED research, as there are few senior PIs in the field. How to lower this barrier;*
    o Initiate formal cross-cutting training initiatives.
    o Highlight the relevance of ED to many other areas of research.
    o Conduct formal training in grant writing.

4.3 Patient and Public Involvement and Engagement

Breakout Groups:

Group 1: PPIE in research design, Moderator – Ulrike Schmidt

Group 2: PPIE in ongoing research and evaluation, Moderator – Annette Ewence

Group 3: Diversity in PPIE, Moderator – Una Foye

Group 4: PPIE in funding, Moderator – David Pan

Group 5: Social Media, Moderator - Petya Eckler

Questions posed:

- ❖ How might PPIE be best incorporated in the design of research projects?
- ❖ How can PPIE be best incorporated into ongoing research and research evaluation?
- ❖ How can people with a variety of lived experiences be approached and engaged to be involved in the research process?
- ❖ How can PPIE be best integrated into funding initiatives?
- ❖ What role could social media play in PPIE?

It was highlighted that the engagement level from people with lived experience of ED as well as carers was very high and placed the ED field in a privileged position to do outstanding PPIE, which would provide value for people involved as well as for researchers. Workshop participants made the following recommendations to encourage and improve PPIE in ED research;

Research design

- Consider level of engagement ahead of starting a research project and when advertising for PPIE support, to get skills and interests of the respondents mapped.
  - o Service user PPIE through existing advisory groups can be good for many questions, while other questions need bespoke input from people with very specific lived experiences (e.g. those who have had specific comorbidities or treatment experiences).
  - o Social media is a channel for quick feedback and easy access to a large number of people, which can be used to build research questions from the ground up.
- Conduct targeted PPIE prioritisation exercises for ED research to identify specific priorities, e.g; treatment needs, most important research questions or the use of specific drugs or novel technology.

Ongoing research and evaluation

- Take advantage of existing advisory groups through charities or research organisations.
- Be prepared to change outcomes and priorities in response to PPIE input to focus on what is meaningful.
- Focus on 360-degree feedback throughout projects to ensure change is incorporated.

Representation:

- Diversity, both in terms of PPIE participants and researchers was highlighted. To ensure input across the spectrum of people living with ED, there is a need to reach marginalised

groups and amplify voices that are not heard instead of engaging the same group repeatedly.
- Taking a respectful approach to people with lived experience and aiming for mutual benefits. The expenses and time of people engaged in PPIE should be appropriately compensated, and this is particularly important in making it accessible to people from marginalised communities.

Funding

- Explicitly encourage lay summaries and accessible language across disciplines.
- Consider different approaches for different types of research.
- Dedicated funding in ROs for PPIE in research design as some researchers are currently experiencing difficulties in conducting the appropriate PPIE work at the pre-application stage.
- Include training and practice for PPIE representatives in research proposals, and recognise excellence in PPIE also for people with lived experience.
- Improve visibility of PPIE groups to researchers, and vice versa, to increase access and involvement.
- Develop meaningful and innovative ways to encourage engagement in Panel meetings.
- Provide a clearer mandate by funders for inclusion of PPIE in the development of grants and in the discussion and scoring of proposals.

Social media

- Highlight social media as an area for support for the ED community.
- Identify which channels and approaches work in order to harness the positive elements that will enable;
    o communication with hard-to-reach people,
    o ease communication for a wide range of neurodiverse people,
    o reach beyond Western centric bias.
- Carefully identify and consider the bias found in data collected through social media.
- Work with research ethics committees to ensure framework is in place for emerging technology development.

4.4 Harnessing existing and emerging data

Breakout Groups:

Group 1: Current large cohorts and data harmonisation, Moderator – Ann John

Group 2: Current biological and genomics data, Moderators – Stephen O'Rahilly and Gerome Breen

Group 3: Future cohorts and measurements, Moderator – Sarah Byford

Group 4: Clinical trials, Moderator – Khalida Ismail

Questions posed:
- ❖ Is the ED research community aware of existing data sources and how can awareness, uptake and use be maximised?
- ❖ How can data from animal research best be collated and made available?
- ❖ How can the need for data harmonisation be best addressed?

❖ What measures/data/samples are missing from existing surveys/cohorts/studies that are of importance and need to ED research?
❖ What are the needs in terms of clinical trials?

The breakout groups discussed the above questions from different perspectives and summarised the top priorities in a joined discussion. Workshop participants made the following recommendations to harness existing and emerging ED related data;

Awareness of existing data

- Promote greater awareness of what exists in terms of relevant cohorts and animal studies from adjacent fields, as well as the DATAMIND initiative.
- Leverage large scale longitudinal data, both in UK and internationally, to conduct analyses based on polygenetic risk scores.

Improved measures and data capture

- Develop and (where possible) harmonise future questionnaires to capture relevant information.
- Optimise measurements of recovery and treatment outcomes.
- Incorporate questions regarding avoidant restrictive food intake disorder (ARFID) to capture prevalence data.
- Decide on minimum phenotyping datasets and which standard instruments should be used.
- Include and standardise measurements of a wide range of sociocultural aspects of ED, such as cultures, attitudes, belief, loneliness, isolation and perception of illness. Take care to adapt measures in response to input, such as PPIE feedback.
- Measure peripheral biomarkers and consider the effects of starvation when interpreting the complex metabolic data.

Clinical trials and health data

- *There are a limited number of RCTs in the UK and elsewhere, and intervention studies in adolescents are particularly needed. The gap can be partially filled by naturalistic/routine data, captured across community services, emergency departments, hospitals and private sector, however harmonisation is challenging due to issues with quality, completeness and application processes. To lower barriers for RCTs, areas for improvement were suggested;*
    o Work more closely with carers to support recruitment.
    o Increase formalised sites of recruitment.
    o Adapt low intensity behavioural interventions used for obesity to ED research.
    o Conduct scoping reviews of early phase RCTs that are about to start, e.g. feasibility studies, in order to understand what can be done to move them forward in the process.
- To move forward with clinical trials, it is paramount to understand the mechanisms, and target identification can be aided by findings in adjacent fields, such as obesity and other mental health conditions.

Cohort data

- Target cohort studies to investigate different aspects of ED;
    o Specialised ED cohort to investigate relapse, life course management and changing over time.
    o Larger more general cohorts to identify risk factors and facilitate early detection, such as birth cohorts, and to capture the full range of EDs.
- Address co-morbidities and sociocultural aspects in future studies.

- Ensure future cohort data can be easily linked to other types of data.

Data diversity

- Incorporate men and other under-represented groups in the data captured, including routine clinical data.
- Move away from Western measures while considering broader cultural aspects.

Strategic messaging

- Harness the expertise of PPIE representatives and establish networking areas to enable powerful collaborative statements with researchers and clinicians.
- Move away from individual responsibility and advocate for a population health approach in the current strategic messaging, both around ED and obesity. Focus on the need for treatment in combination with an environment that promotes positive eating behaviour.

4.5 Current and future treatments

Breakout Groups:

Group 1: Biological treatments, Moderator – Suzanne Dickson

Group 2: Psychological treatments, Moderator – Janet Treasure

Group 3: Art and culture in treatment, Moderator – Heike Bartel

Group 4: Novel technology, Moderator – Helen Bould

Group 5: Learnings from the pandemic, Moderator – Ulrike Schmidt

Questions posed:

- ❖ How could research help increase effective treatment and prevention options for ED?
- ❖ What are the barriers in patients accessing treatment and how could research help in lowering these barriers?
- ❖ How could online treatment be utilised to improve access to and scalability of treatment?

The breakout groups discussed the above questions from different perspectives and summarised the top priorities in a joined discussion. Workshop participants made the following recommendations to advance research into treatment of ED:

Biological/psychological treatments

- Focus on understanding co-morbidities of ED to facilitate the understanding of personalised treatment pathways.
- Greater understanding of risk factors to aid early detection and prevention.
- Focus on understanding disease mechanisms in order to direct treatment efforts. More research is needed on potential biological treatment avenues, such as metreleptin and other hormonal treatments, SSRIs, GDF15, cannabinoids, microbiota and combination therapies.
- Validate targets and investigate pathways implicated in clinical findings using animal models.
- *Interesting avenues of mechanistic research relevant for therapeutics suggested were:*
  - o Hypothalamic influences on ED.

- o The relationship between hormonal influences and mood.
- o Starvation models, both animal and human.
- o Sex hormones and sex differences.
- o Distinction between ED disorders to solidify evidence base for phenotypic interventions.
- o Implications of inflammation in ED.

Online treatments and learning from the Covid-19 pandemic

- *Adolescents and young adults are in a state of transition, both physiologically, mentally and physically and online treatments can be beneficial in this regard. The increased incidence of ED during the Covid-19 pandemic, as well as the deterioration of existing patients (of all ages), meant an increasing burden on already struggling services, and loneliness was viewed as a key contributor. The pandemic also meant that new technology was introduced rapidly. The following recommendations were made;*
- Understanding stigma and perceptions of EDs which can hinder detection and help-seeking
- Research to help develop and evaluate training for non-specialists to promote early identification.
- Enable people to stay with the same treatment team during transition periods, by personalising online treatment according to risk as high risk is difficult to monitor online. Pay attention to isolation effects.
- Deploy learnings from the pandemic in order to negotiate better service transitions, when people move.
- Focus research on co-designing technology that works with patients, to avoid possible caveats, such as people being disturbed by their own image during video calls and difficulties in safely monitoring physical health remotely.

Arts and culture

- *Music and arts therapy was highlighted as an approach that promoted mutual recovery for families and might be beneficial for moderate ED.*
- Use arts and culture to change the narrative of ED and promote prevention via:
  - o Understanding how to raise awareness through various media as ED often present with common mental health symptoms, and people are unaware of the underlying issues.
  - o Encouraging people to seek help earlier.
  - o Preventing escalation of symptoms.
  - o Changinghow eating and body is viewed.
  - o Widening the range of media from writing and reading to include for instance animation, comedy and film.
  - o Understanding how art in itself can reinforce stereotypes to avoid pitfalls.
- Promote collaboration across disciplines to broaden the evidence base on these interventions.

Novel technology

- Strengthen evidence base for novel technology, such as smartphones, apps, virtual reality, neuromodulation and machine learning in order to facilitate implementation in the NHS.
- Conduct strong and meaningful PPIE on these technologies in order to understand user need and motivation.
- Work with relevant stakeholders to mitigate difficulties in assessment and approval for home-based intervention apps that can be complementary to clinical follow-up.

- Bridge clinicians with academics to optimise the use of novel technology in understanding ED and potentially identify and deliver treatment.

Interventions delivered by non-clinicians and peer support

- Increase understanding of safe digital, hybrid or group-based brief interventions (including support for people on waiting lists), which could be delivered by supervised non-clinicians.
- Evaluate the impact (i.e. benefits and potential harms) of peer support interventions (for patients, carers and the peer support workers themselves).
- Identify what treatment approach works for who, consider patient preferences and measure drop-out rates in any self-help interventions.

5. Conclusions and key priorities

When summarising the outcomes from the Workshop a set of inter-linked top-level priorities were identified to aid progress in ED Research;

1. **Inter-disciplinary research**

There was a strong need identified for engagement between disciplines within the eating disorder research field, to create an inclusive research environment that takes into account the biological, psychological and sociocultural aspects of these complex disorders.

In addition, there was a need for stronger engagement with adjacent fields such as metabolic disorders (e.g., obesity, diabetes), mood and anxiety disorders, addiction, neurodevelopmental conditions (e.g., autism, ADHD), and other mental health conditions.

2. **Leveraging existing datasets and ensure ED research input into future cohorts**

It was highlighted that there is a lack of awareness of relevant data in existence, especially in adjacent fields and for animal data.

It was also highlighted that measurements of eating behaviour and biological data related to EDs were missing from many existing cohorts, and there is an urgent need to include these to increase the relevance to ED research.

It was emphasised that the ED research community should engage in discussions on how to include ED measures in future cohorts and updates of large datasets.

3. **Harmonisation of measurements and approaches**

It was clear that there is a need for large scale efforts on increasing the availability, relevance and usability of currently collected data including:

- Completeness, quality and harmonisation of routinely collected clinical data from various sites.
- Standardisation and innovation of measurements and assessments methods to capture clinically relevant behaviour.
- Harmonisation between animal and human research to facilitate translation between species.

4. Diversity and under-represented groups

There is currently a lack of data on male, middle aged and older people, ethnic minorities, LGBTQ+ individuals, and neurodiverse people living with ED, which needs to be resolved.

There is also a lack of information about beliefs, cultural and socioeconomic factors in ED data sets, which needs to be included.

5. Leveraging the expertise and engagement of people with lived experience, including carers

There is a strong need to fund engagement of people with lived experience, including carers, throughout the research process to ensure that research is relevant and of high quality.

People with lived experience should be engaged in treatment and intervention design given the valuable role they play in reducing stigma and increasing the strategic visibility of ED research.

6. Building research capacity and offering support across all career stages

As there are very few research centres dedicated to EDs in the UK there is a need for stronger support for ECRs. This could be delivered through the establishment of;

- Formal cross-cutting training and mentoring initiatives.
- Networking support across institutions and research fields.
- Funding targeted at ECRs to enable them to spend more time on research.

Funding for eating disorder clinicians with a research background (e.g. clinician fellowships) is also needed to further build capacity.

7. Prevention, Treatment and Services

To improve clinical outcomes for patients with eating disorders, there is a need for a broad range of intervention studies (from proof-of concept/feasibility to efficacy/effectiveness) assessing psychological and biological interventions, both stand-alone or as adjuncts to established treatments. There is also a need for studies on novel targets for prevention. Across the spectrum of eating disorders this should include studies of:

- Brief interventions, especially those that can be delivered online or in hybrid formats.
- Novel technology-based interventions (e.g. those delivered via virtual reality, gamified interventions).
- Novel mechanism-based psychological approaches (e.g. different cognitive trainings, exposure treatments and others).
- Novel biological and brain-based approaches (e.g. pharmacological, brain stimulation).
- Novel ways of delivery of interventions (e.g. peer- vs therapist guided interventions).
- Interventions in different settings (e.g. in-patients) and populations (early stage versus established late stage illness).

ANNEX

Annex 1 – Agenda

	Eating Disorders (ED) Research Workshop – Day 1	
13.00	Introduction	Welcome by Workshop Chair Jeremy Hall
13.30	**Session 1 - Mechanisms of ED**	Speakers: • Fernando Fernández-Aranda – Psychological mechanisms of ED and co-morbidities • Guido Frank - Neurophysiology of ED • Johannes Hebebrand - Biological mechanisms of ED • Phillippa Diedrichs – Sociocultural aspects of ED
14.10	**Break**	
14.20	Breakout Groups: **Group 1: Psychological mechanisms** Moderator –Ulrike Schmidt **Group 2: Neurophysiological mechanisms** Moderator – Guido Frank **Group 3: Biological mechanisms** Moderator – Stephen O'Rahilly **Group 4: Sociocultural mechanisms** Moderator – Phillippa Diedrichs **Group 5: Mechanisms of treatment** Moderator – Janet Treasure	Questions to be addressed within each group: • Which underpinning mechanistic areas would be best explored to offer the greatest opportunity to strengthen research into ED? • What data is missing to allow the field to progress? • What are the greatest requirements needed to make progress in the field (e.g partnerships/collaborations/infrastructure/ resources/methods)?
15.20	**Break**	
15.30	Reports and summary	Reports from each breakout group provided to the plenary group to synthesise priority areas and needs to progress research into mechanisms of ED.
16.15	**Session 2 – Career progression** Panel discussion with Early Career Researchers Chaired by Jeremy Hall	Panel participants: • Caitlin Lloyd • Dawn Branley-Bell • Samuel Chawner • Margaret Westwater Questions to be addressed: • What are the barriers to career progression in the field of ED research? • How can these barriers be lowered?
17.00	**End of Day 1**	

		Eating Disorders (ED) Research Workshop – Day 2	
12.30	**Session 3 – Patient and public involvement and engagement (PPIE)**	Speakers:	
		Una Foye and Helen Missen - Current state and future opportunities for PPIE in ED research	
12.40	Breakout Groups	Questions to be addressed:	
	Group 1: PPIE in research design Moderator – Ulrike Schmidt	• How might PPIE be best incorporated in the design of research projects?	
	Group 2: PPIE in ongoing research and evaluation Moderator – Annette Ewence	• How can PPIE be best incorporated into ongoing research and research evaluation?	
	Group 3: Diversity in PPIE Moderator – Una Foye	• How can people with a variety of lived experiences be approached and engaged to be involved in the research process?	
	Group 4: PPIE in funding Moderator – David Pan	• How can PPIE be best integrated into funding initiatives?	
	Group 5: Social Media Moderator - Petya Eckler	• What role could social media play in PPIE?	
13.05	Reports and summary	Reports from each breakout group provided to the plenary group to synthesise priority areas and needs to progress PPIE in ED research.	
13.20		Break	
13.30	**Session 4 – Harnessing existing and emerging data**	Speakers:	
		• Ann John – Future data collections and measures	
13.50	Breakout Groups: to discuss topic	Questions to be addressed:	
	Group 1: Current large cohorts and data harmonisation Moderator – Ann John	• Is the ED research community aware of existing data sources and how can awareness, uptake and use be maximized?	
	Group 2: Current biological and genomics data Moderator – Stephen O'Rahilly and Gerome Breen	• How can data from animal research best be collated and made available?	
	Group 3: Future cohorts and measurements Moderator – Sarah Byford	• How can the need for data harmonization be best addressed? • What measures/data/samples are missing from existing surveys/cohorts/studies that are of importance and need to ED research?	
	Group 4: Clinical trials Moderator – Khalida Ismail	• What are the needs in terms of clinical trials?	
14.35	Reports and summary	Reports from each breakout group provided to the plenary group to synthesise priority areas and needs to improve accessibility, utilisation and harmonisation of current ED data as well as considerations for future data collection.	
15.00		Break	

15.10	**Session 5 – Current and future treatments**	Speaker: • Janet Treasure – Research gaps in treatment of ED
15.30	Breakout rooms to discuss treatment **Group 1: Biological treatments** Moderator – Suzanne Dickson **Group 2: Psychological treatments** Moderator – Janet Treasure **Group 3: Art and culture in treatment** Moderator – Heike Bartel **Group 4: Novel technology** Moderator – Helen Bould **Group 5: Learnings from the pandemic** Moderator – Ulrike Schmidt	Questions to be addressed: • How could research help increase effective treatment and prevention options for ED? • What are the barriers in patients accessing treatment and how could research help in lowering these barriers? • How could online treatment be utilised to improve access to and scalability of treatment?
16.30	Reports and summary	Reports from each breakout room to synthesize priority areas and needs in order to improve research on treatment opportunities, access and prevention of eating disorders.
16.55	**Conclusions**	
17.00	**End of Workshop**	

Annex 2 – List of attendees

Workshop Steering Group			
Name	**Affiliation**	**Name**	**Affiliation**
Professor Jeremy Hall (Chair)	Cardiff University	Dr Kelly Makarona	Medical Research Foundation
Professor Tim Dalgleish	University of Cambridge	Dr Nadia Micali	University College London
Dr Petya Eckler	University of Strathclyde	Professor Sir Stephen O'Rahilly	University of Cambridge
Annette Ewence	Economic and Social Research Council	Dr David Pan	Medical Research Council
Dr Karen Finney	Medical Research Council	Dr Susanna Roberts	Medical Research Foundation
Catherine Gilmore	Arts and Humanities Research Council	Erin Shearman	Department of Health and Social Care
Lucy Hackett	Arts and Humanities Research Council	Professor Ulrike Schmidt	King's College London
Professor Ann John	Swansea University	Alison Tingle	Department of Health and Social Care
Jonathan Kelly	Beat	Dr Siv Vingill	Medical Research Council

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Workshop Attendees			
Name	**Affiliation**	**Name**	**Affiliation**
Suzanne Baker		Professor Khalida Ismail	King's College London
Professor Heike Bartel	University of Nottingham	Dr Tom Jewell	Maudsley Hospital
Professor Kam Bhui	University of Oxford	Dr Gemma Johns	NHS Wales
Dr Helen Bould	University of Bristol	Mr Jonathan Kelly	Beat
Dr Dawn Branley-Bell	Northumbria University	Ms Victoria Kensdale	Beat Volunteer
Professor Gerome Breen	King's College London	Professor Anna Keski-Rahkonen	University of Helsinki
Linda Bullivant	Department of Health and Social Care	Rashmi Kumar	
Professor Sarah Byford	King's College London	Professor Anna Lavis	University of Birmingham
Professor Iain Campbell	King's College London	Dr Caitlin Lloyd	Columbia University
Dr Valentina Cardi	King's College London	Dr Kelly Makarona	Medical Research Foundation
Mr Dave Chawner	Comedy For Coping	Miss Ellen Maloney	Beat Volunteer
Dr Samuel Chawner	Cardiff University	Dr Sarah Markham	King's College London
Professor Sylvane Desrivieres	King's College London	Miss Katie McKenzie	Beat Volunteer
Professor Susanne Dickson	University of Gothenburg	Professor Niamh McNamara	Nottingham Trent University
Professor Kelly Dickson	University College London	Helen Missen	F.E.A.S.T representative (UK)
Professor Phillippa Diedrichs	University of the West of England	Professor Valeria Mondelli	King's College London
Elena Eu		Ms F. Murphy	Beat volunteer
Annette Ewence	Economic and Social Research Council	Dr Dasha Nicholls	Imperial College London
Suzanne Farrell	NHS England	Dr David Pan	Medical Research Council
Professor Fernándo Fernandez-Aranda	University of Barcelona	Professor Emma Rich	University of Bath
Dr Karen Finney	Medical Research Council	Dr Susanna Roberts	Medical Research Foundation
Mrs Alison Foggon	Beat Volunteer	Dr Francesca Solmi	University College London
Professor John Fox	Cardiff University	Dr Victoria Swann	Medical Research Council
Dr Una Foye	King's College London	Dr Jacinta Tan	Oxford Health NHS Foundation Trust
Professor Guido Frank	University of California San Diego	Professor Kate Tchanturia	King's College London
Lucy Hackett	Arts and Humanities Research Council	Professor Stefan Trapp	University College London
Dr Amy Harrison	University College London	Professor Janet Treasure	King's College London
Professor Dr. Med. Johannes Hebebrand	University of Duisburg-Essen	Dr Siv Vingill	Medical Research Council
Professor Dr. Med. Beate Herpertz-Dahlmann	RWTH Aachen University	Professor Glenn Waller	University of Sheffield
Professor Marion Hetherington	University of Leeds	Dr Ursula Wells	Department of Health and Social Care
Professor Suzanne Higgs	University of Birmingham	Dr Margaret Westwater	Yale University
Dr Hubertus Himmerich	King's College London	Professor Giles Yeo	University of Cambridge
		Dr Zuo Zhang	King's College London

Annex 3 – Workshop Ground Rules

Ground rules for Eating Disorder Research Workshop

- For those who have personal experience of ED – please only speak as openly as you feel comfortable. It's ok to avoid discussing specific topics if you are not comfortable to do so.

- If you would like to take a break at any point or you need to leave the workshop, please do so. Please just let us know by sending Jonathan Kelly a direct message in the chat.

- All contributions are appreciated —there are no right or wrong comments. Please listen to and respect others' views even if you have a different perspective or disagree.

- Please avoid sharing specific details about symptoms or behaviours that might encourage unhealthy comparisons or be triggering for anyone else. This includes not talking about specific weight/BMI numbers (for example saying 'a very low BMI' rather than 'a BMI of X').

- Please protect others privacy by not discussing the details of other people's experiences outside of this group.

- If there is any jargon or acronyms used during the workshop that you are not familiar with, please don't hesitate to ask what they mean – either verbally or in the chat.