Innovation
Research and Development Newsletter

Cost-effectiveness of a specialist smoking cessation package: SCIMITAR+ study

Sexual Orientation Monitoring Survey

Online resources for people who self-harm: FRESH START

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Editorial

Editorial issue 41 Innovation

Welcome to our 41st edition of Innovation. We are gearing up to support potential COVID vaccine studies that will be coming to our region later in the year. Do consider signing up to take part at https://www.nhs.uk/sign-up-to-be-contacted-for-research.

I am delighted to welcome Melissa Brettell (Mel) to the R&D team. She introduces herself to you in this issue. I am grateful to both Hannah Edwards and Hannah Pearson for all their hard work supporting studies involving school children, their parents and teachers. They have both left the Trust to advance their research careers. The new research assistants, who will be starting in post shortly, will introduce themselves in a future edition of Innovation.

We have a number of articles about dementia this time, namely:

- Perception of behaviour associated with dementia in Acute Hospital
- Dementia assessment tool, Free-cog, and
- Improving the experience of Dementia and Enhancing Active Life (IDEAL study).

This newsletter also contains summaries of the following completed projects:

- Cost-effectiveness of a specialist smoking cessation
- Sexual Orientation Monitoring Survey and
- The Health and Wellbeing Cohort.

Additionally we have articles about online resources for people who self-harm which have come from the FRESH START research programme and an abstract of a publication by one of our clinician’s about their view of Biomarkers in psychiatry.

You may not be aware that LYPFT staff are involved in writing or contributing to around 40 publications per year, many of which are in peer-reviewed (ie high quality) journals. If you would like to know more, take a look at the research webpages on staffnet or the Trust’s website at https://www.leedsandyorkpft.nhs.uk/research/publications/ You will also find all the back copies of Innovation there.

The usual funding deadlines are included.

Do get in touch if you want to send in an article or have any questions or suggestions about research in LYPFT.

Alison Thompson,
Head of Research and Development,
Athompson11@nhs.net or 0113 85 52360.
Aims
To evaluate the cost-effectiveness of a specialist smoking cessation package compared with standard smoking cessation services for people with severe mental illness in England.

Design
Incremental cost-effectiveness analysis was undertaken from the UK National Health Service and Personal Social Services perspective over a 12-month time horizon. Total costs, including smoking cessation, health-care and social services costs and quality-adjusted life years (QALYs), derived from the five-level EuroQol 5-dimension (EQ-5D-5 L), collected from a randomized controlled trial, were used as outcome measures. The bootstrap technique was employed to assess the uncertainty.

Setting
Sixteen primary care and 21 secondary care mental health sites in England.

Participants
Adult smokers with bipolar affective disorder, schizoaffective disorder or schizophrenia and related illnesses (n = 526). Thirty of these participants were recruited in Leeds and York Partnership NHS Foundation Trust.

Intervention and comparator
A bespoke smoking cessation (BSC) package for people with severe mental illness offered up to 12 individual sessions with a mental health smoking cessation practitioner versus usual care (UC). Of the participants who were randomized, 261 were in UC group and 265 were in BSC group.

Measurements
BSC intervention cost was estimated from the treatment log. Costs of UC, health-care and social services and EQ-5D-5 L were collected at baseline, 6- and 12-month follow-ups. Incremental costs and incremental QALY’s were estimated using regression adjusting for respective baseline values and other baseline covariates.

Findings
The mean total cost in the BSC group was £270 [95% confidence interval (CI) = –£1690 to £1424] lower than in the UC group, while the mean QALYs were 0.013 (95% CI = –0.008 to 0.045) higher, leading to BSC dominating UC (76% probability of cost-effective at £20 000/QALY).

Conclusions
A bespoke smoking cessation package for people with severe mental illness is likely to be cost-effective over 12 months compared with usual care provided by the UK’s National Health Service and personal social services.

Jinshuo Li, University of York, jinshuo.li@york.ac.uk
Other researchers:
Caroline Fairhurst, Emily Peckham, Della Bailey, Catherine Arundel, Catherine Hewitt, Paul Heron, Suzanne Crosland, Steve Parrott, Simon Gilbody and SCIMITAR+ collaborative, University of York.
Aims and Hypothesis:
General hospital based Health Care Professionals (HCPs) use very varied language to describe behaviour of people with dementia. Lessons from medicine and other professions tell us that non-uniform communication is a source of error and subsequent poor decision making. Knowing how HCPs communicate behaviour in dementia in a hospital setting may help better understand these potential sources of communication error and identify training needs.

Background:
Around 25% of hospital beds are occupied with people living with dementia. Hospitalised patients with dementia have a high prevalence of distressing symptoms (pain 70%, delirium 66%, depression 35%, anxiety 34%, hallucinations 14% delusions 11%). These symptoms often displayed as behaviour can be challenging for HCPs to interpret. Variations in communicating behaviour may lead to inconsistent understanding of the need, with the potential for missing treatable conditions that drive the behaviour. Standardizing communication and documentation have the potential to improve the quality of information handed over between HCPs which may improve the quality of care and patient outcomes.

Methods:
Qualitative methodology including photo elicitation was used. This is an interview method that uses visual images to elicit comments. A purposive sample of 59 HCPs was selected. This was identified from a range of professional backgrounds, experience levels and medical specialities. They were presented with a photograph and case vignettes depicting 4 behaviours associated with distress (aggression, depression, delirium and psychosis). HCPs were asked to respond to the scenarios as if they were handing over to colleagues or documenting in the medical record. Data were analysed by thematic analysis.

Results:
59 HCPs were interviewed with photo elicitation. Participants recorded their responses in limited time to reflect time constraints in a busy ward environment. 2 HCPs declined to participate in the research. When describing behaviour associated with aggression and depression HCPs were consistent with the language used (49/57). When presented with a delirium less consistency was observed (31/47). While describing psychosis each HCP chose either paranoia or suspiciousness among other descriptions.

Conclusions:
Overall there has been consistency in describing the distress experienced by the patient even though HCPs came from very different roles and specialities. Doctors, Nurses, CSWs and dieticians all described the behaviour alike. Newer staff were more accurate which could be due to dementia training within National Dementia Action Alliance.

Zumer Jawaid, LYPFT, zumerrific.jawaid@nhs.net
Other Researchers:
George Crowther and Syeda Ashar, LYPFT.
The Free-Cog study

A novel hybrid scale for the assessment of cognitive and executive function in dementia.

What was this research about and why was it important?

An estimated 1 in 14 people over the age of 65 living in the UK have dementia. Although we are yet to find a cure, early diagnosis and interventions can allow patients to live independently for longer. Therefore, early and efficient diagnosis is one of the most important tools in a clinician’s arsenal.

However, diagnosis can be complicated by the fact that many types of dementia exist and, the specific pattern of damage within a person’s brain will affect how individual symptoms present. Therefore, any test needs to be able to detect and pinpoint a range of symptoms.

Being familiar with a range of clinical tests used to diagnose dementia, Professor Alistair Burns and his team noticed a problem with these existing tools. Not only were the majority subject to copyright, thus requiring payment for use, no single test combined measures of cognition (memory, visual and spatial function, language and fluency) with measures of executive function (social functioning, travel, self-care and safety in the home).

It was this observation that sparked the idea for Free-Cog; a free-to-use assessment tool which combined tests of cognition and executive function into one global test, designed to be suitable for use in a busy clinical environment.

What did our patients say about taking part?

Patients and members of the public were involved in developing this project at a very early stage. Professor Burn’s team worked with The Alzheimer’s Society’s Research Network to ensure that the format and wording of the test questions were tailored to patient’s needs.

This involvement appeared to be beneficial, since many patients who were involved in trialing out the Free-Cog assessment commented that they liked its ‘conversational style’ and that they felt more relaxed and confident taking this test than some other more commonly use assessments.

“It didn’t feel like an examination, it felt more like a TV quiz and was much better than the other assessment”

“My father seemed more visibly relaxed completing the Free-Cog study then the previous assessment”

What did the study find?

In total, 956 participants from across the UK, including 113 from LYPFT, took part in trialing the Free-Cog assessment. Many Greater Manchester patients fed back to our research nurses saying they found the experience interesting and enjoyable.

The study showed that Free-Cog was similar to existing, routinely used, tests in its ability to differentiate between patients with Mild Cognitive Impairment (MCI) and Dementia and between healthy patients with no cognitive diagnosis and those with MCI.
Despite some limitations, including a lack of specificity inherent in being a global scale and minimal written instructions, designed to make it easier for busy clinicians but which may be less acceptable for inexperienced staff; the Free-Cog assessment performed well and may have a number of benefits over current routinely used tests.

**How will it improve services in the future?:**

This tool is free to use, measures both cognitive and executive functioning and is less likely to be perceived as a ‘test’ by patients meaning overall performance may be less impacted by patient anxiety.

Combine these benefits with the finding that its performance is on par with other more commonly used tests and that it has a telephone consultation version (Tele Free-Cog) which also discriminates between patient groups, this makes Free-Cog a particularly powerful tool which may also adapt well to non-face-to-face setting.

The Free-Cog will remain freely available in perpetuity. It is available to anyone interested in trialling it, translating it or validating it

Alistair Burns, University of Manchester, Alistair.Burns@manchester.ac.uk
Sexual Orientation Monitoring Survey

Background to the Survey

There are clear health disparities for lesbian, gay, bisexual (LGB) people in the UK, yet without accurate and suitable monitoring data it is difficult to know the true extent of these disparities.

A key recommendation of LGB&T Public Health Outcomes Framework (Williams et al., 2013) published in the UK was that sexual orientation should be routinely monitored in health and social care to allow for a better understanding of health disparities facing the LGBT community when accessing health care.

Academic research in the USA has suggested that staff greatly over-estimating the amount of discomfort collecting this information would cause patients. Other barriers to collecting sexual orientation information are presumptions about sexual behaviour, confidentially and methods of data collection.

To date there has been no empirical study investigating staff opinions on the collection of sexual orientation information in the UK.

What did we do?

This study invited NHS staff from 12 trusts across England to complete a survey about their perceptions of collecting sexual orientation monitoring information, to allow us to better understand how NHS staff feel about collecting this information. This is a summary of responses from your Trust.
76 staff responded to the survey

67% identified as heterosexual and 26% identified as LGBTQ+ including gay, lesbian, bisexual, pansexual and queer.

48.7% of staff reported feeling comfortable (or very comfortable) collecting sexual orientation monitoring information from patients.

23.7% of staff agreed they felt awkward or embarrassed when asking questions about sexual orientation.

25% of staff reported usually or always collecting sexual orientation monitoring data from patients.

52.6% of staff reported they had received LGBT awareness training in the last 5 years.

35.5% of staff agreed that patients would be offended if asked for their sexual orientation.

63.2% of staff agreed that sexual orientation information was important for the provision of healthcare and

59.2% agreed it was important for patient treatment and care.
Despite recent fears about online influences on self-harm, the internet has potential to be a useful resource, and people who self-harm commonly use it to seek advice and support. The aim of this research was to identify and describe UK-generated internet resources for people who self-harm, their friends or families, in an observational study of information available to people who search the internet for help and guidance.

The different types of advice from different websites were grouped according to thematic analysis. A large amount of advice and guidance regarding the management of self-harm was found. The most detailed and practical advice, however, was limited to a small number of non-statutory sites. A lay person or health professional that searches the web may have to search through many different websites to find practical help.

The findings therefore provide a useful starting point for clinicians who wish to provide some guidance for their patients about internet use. Websites change over time and the internet is in constant flux, so the websites identified would need to be reviewed before making any recommendations to patients or their families or friends.

This work is part of a programme of research, FReSH START, funded by the National Institute for Health Research through Programme Grants for Applied Health Research £2.5m over 6 years. LYPFT manages this grant.

To read the full report please visit: https://www.mdpi.com/1660-4601/17/10/3532/htm

Elspeth Guthrie, University of Leeds, e.a.guthrie@leeds.ac.uk
Other Researchers
Daniel Romeu, Cathy Brennan, Kate Farley and Allan House.
Hello my name is... Melissa Brettell

I recently joined the Trust’s Research and Development Team as a Research Assistant.

Prior to this, I worked in a Child and Adolescent Inpatient Hospital as an Assistant Psychologist. I worked with a range of young people experiencing various mental health issues including schizophrenia, bipolar disorder and anorexia nervosa. My role involved carrying out assessments and delivering evidence based therapeutic interventions. This work highlighted to me the invaluable role that research plays in improving the wellbeing of those struggling with their mental health, as it is vital for informing such interventions etc.

I completed my psychology degree at the University of Sheffield. While studying, I worked as a volunteer for Adullam Foundations – this is a charity that supports individuals with mental health issues alongside providing them with accommodation. I thoroughly enjoyed my time in this role and feel very passionate about supporting service users.

I am very excited to work in the Research and Development team for LYPFT and feel lucky to have the opportunity to help in the delivery of various National Institute for Health Research studies.

Melissa Brettell, LYPFT, Melissa.brettell@nhs.net

#hello my name is…

Biomarkers in psychiatry: a clinician’s viewpoint

Introduction
The dearth of biomarkers limits the precision of our research into pathogenesis of psychiatric disorders and has slowed down the development of new drugs. In clinical practice, it undermines the validity of psychiatric diagnoses and hampers the delivery of personalized treatment.

Areas of controversy
The cross-sectional and longitudinal observation of psychopathology is the bedrock of current clinical practice. Are psychiatric biomarkers advanced enough to supplant it?

Growing points
The need for biomarkers of psychiatric disorders has become more acute with the advent of new treatments which require precision and an individualized approach.

Areas timely for developing research: Identification and deployment of intermediate phenotypes in classification, research and clinical practice of psychiatry.

The full article can be viewed in the British Medical Bulletin here: https://doi.org/10.1093/bmb/ldaa019

Tariq Mahmood, LYPFT, tariq.mahmood5@nhs.net
The Health and Wellbeing Cohort (HWB) is integral to tackling the health inequality that people with severe mental illness (SMI) experience. It is a project being run by the University of York and it has been happening across 26 secondary care trusts and in over 300 GP practices in England. HWB started out in 2016 by asking people with conditions such as schizophrenia or bipolar disorder to complete a survey exploring their physical health. HWB aimed to understand people’s health and to challenge the stereotype that people with SMI are not interested or not willing to modify health behaviours. We asked people about their diet, smoking, exercise, and whether they would be interested to do something about it, such as quitting smoking. Importantly, most participants have asked to be contacted again about related research.

Meanwhile, the Closing the Gap (CtG) Network was launched in February 2019. The CtG Network will use scientific rigour and principles of sharing, outward-facing, and inclusivity to close the gap on health inequalities for people with SMI. The Network will explore innovative approaches, such as digital technologies and the natural environment, to understand how they can be used to improve health and wellbeing. The HWB cohort is a central resource that allows service users, healthcare professionals, and researchers to connect and to collaborate. This is an exciting time for research in the area of SMI and physical health and wellbeing.

Five years after the launch of HWB Cohort, the 10,000th person took part. We can now say that many in fact do want to change their health behaviours and to lead healthy lives. The data are currently being analysed for publication, but we have some exciting early findings to share with you. Together with the HWB team, Paul Heron, a Research Fellow at the University of York, has produced an infographic booklet showing some early data of the people who took part from Leeds and York Partnership NHS Trust. https://drive.google.com/file/d/1hJ09mtZqTgpINrA7l99eJJSAT9dIX5Yt/view

Paul Heron, University of York, paul.heron@york.ac.uk
At Leeds and York Partnership NHS Trust, 374 participants have taken part.

Service users were invited to discuss taking part with a researcher following routine outpatient appointments thanks to signposting from clinicians. Those receiving care in our inpatient services were also approached and invited by researchers to take part.

Surveys were also sent out to clinicians to complete with their service users directly in a wide range of Trust services including AOT, Physical Health Clinics, and Supported living houses.

To ensure the survey reached more service users, we posted the survey direct to eligible patients after screening a number of clinician’s caseloads. This route however was limited to only those clinicians who gave us permission to screen.

The survey was flexible in that not everyone had to sign up to being contacted in the future which may have encouraged some to take part who didn’t want to provide personal details. We found that the service users that took part were more than willing to share their physical health behaviours and for some it appeared to act as a prompt to consider changes they had thought about before but not acted on such as alcohol intake and smoking status.

Crystal-Bella Romain-Hooper, LYPFT, c.romain-hooper@nhs.net
The NIHR Clinical Research Network Portfolio is a database of studies that shows national clinical research study activity. Clinical trials and other well-designed studies involving the NHS, funded by the NIHR, other areas of government and non-commercial partners are automatically eligible for portfolio adoption. Studies that are adopted on to the portfolio can access infrastructure support and NHS service support costs to help with study promotion, set-up, recruitment, and follow-up.

The Research Design Service (https://www.rds-yh.nihr.ac.uk/) provides guidance and support that you will need to access when making an application for NIHR funding. They also provide funding to enable service users, carers and the public to contribute to the development of your research bid.

**The NIHR has launched a new call inviting applications to better understand and manage the health and social care consequences of the global COVID-19 pandemic beyond the acute phase; to help mitigate the impact of subsequent phases of the pandemic and its aftermath.**

This new call sits alongside the current joint UKRI/NIHR rolling research call for ‘urgent’ COVID-19 related research which will have an impact within 12 months. Find out more here: https://www.nihr.ac.uk/documents/nihr-commissioned-call-specification-document-covid-19-recovery-and-learning/24969

**Funding streams:**

1. **Efficacy and Mechanism Evaluation (EME):** Researcher-led and aims to improve health/patient care. Its remit includes clinical trials and evaluative studies.

2. **Health Services and Delivery Research (HS&DR):** Funding research to improve the quality, effectiveness and accessibility of the NHS, including evaluations of how the NHS might improve delivery of services. It has two work streams, researcher-led and commissioned.

3. **Health Technology Assessment (HTA):** Funds research to ensure that health professionals, NHS managers, the public, and patients have the best and up-to-date information on the costs, effectiveness, and impacts of developments in health technology.

4. **Invention for innovation (i4i):** Funds research into advanced healthcare technologies and interventions for increased patient benefit in areas of existing or emerging clinical need.

5. **Programme Grants for Applied Research:** To produce independent research findings that will have practical application for the benefit of patients and the NHS in the relatively near future.

6. **Public Health Research (PHR) Programme:** Funds research to evaluate non-NHS interventions intended to improve the health of the public and reduce inequalities in health.

7. **Research for Patient Benefit (RfPB):** Generates research evidence to improve, expand and strengthen the way that healthcare is delivered for patients, the public and the NHS.

For further details about funding opportunities through the NIHR, visit: https://www.nihr.ac.uk/researchers/funding-opportunities/

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<th>Funding stream</th>
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<td>Efficacy and Mechanism Evaluation (EME)</td>
<td>Commissioned (Stage 2) - 03 Nov, 1pm</td>
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<td>HTA Commissioned Calls</td>
<td>Commissioned (Stage 1) - 02 Dec, 1pm</td>
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<td>Commissioned (Stage 1) - 06 Jan, 1pm</td>
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<td>Public Health Research (PHR) Programme</td>
<td>Commissioned (Stage 2) - 17 Nov, 1pm</td>
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An effective means of involving people with dementia and carers in the research programme was developed by creating and facilitating the ALWAYs (Action on Living Well: Asking You) group. This ensured meaningful participation in all aspects of the programme, from developing questionnaires and interview schedules to interpreting and disseminating findings.

A central role of psychological factors in relation to ‘living well’ with dementia was developed for both people with dementia and carers. While other domains such as physical health and social resources are important, when modelled together using data from a large cohort, psychological factors dominate. ‘Living well’ was defined as a composite of quality of life, satisfaction with life and well-being. The initial systematic review indicated that existing evidence did not provide clear recommendations: sufficient evidence was available only for quality of life, and showed that many factors have small effects on quality of life. The model developed from IDEAL data, in contrast, provides clear evidence-based indications about where to target efforts aimed at promoting ability to ‘live well’.

A novel evidence on reciprocal influences on well-being within dementia caregiving dyads was presented. Having modelled ‘living well’ separately for people with dementia and carers, we examined the way in which each member of the dementia caregiving dyad influences the ability of the other to ‘live well’. Few studies have considered even the influence of one member on outcomes for the other, and we are among the first to directly address reciprocal influences. We adapted the actor-partner independence model and, uniquely, were able to include in the model those people with dementia who had no carer participating in the study. We presented evidence that depression and loneliness, when occurring in either member of the dyad, influenced outcomes for both members. In contrast, perceptions of relationship quality influenced outcomes only for the individual holding those perceptions. This has clear implications for refining guidance to practitioners to enable them to target interventions so as to achieve optimum benefit.

Issues of health inequality were addressed through further fine-grained analyses of cohort data. A clear relationship between area-level deprivation indices and individual scores on measures of ‘living well’ was demonstrated, with people in less-deprived areas scoring better. This emphasises the need to consider social and environmental influences on ‘living well’ and how people living with dementia in more deprived areas might be better supported. Similarly demonstrated were the differences in ability to ‘live well’ according to the specific type of dementia, showing that people diagnosed with Parkinsonian dementias and their carers scored on average more poorly on indices of ‘living well’ than those with other dementia diagnoses. This is thought to be because of the additional physical disabilities they face, and in many cases, the long period of living with disability prior to the onset of cognitive decline. Again, this evidence supports targeted resourcing to those in greatest need. It also identified new research questions about ‘seldom heard’ groups, for which further funding to explore these questions was obtained.

IDEAL study, University of Exeter, IDEAL@exeter.ac.uk
Innovation is a newsletter for sharing and learning about health research. This includes information about projects being carried out in your area. As such we welcome any articles or suggestions for future editions.

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Research Forum 2020: Register to attend

Date: 12 November 2020  
Venue: Online webinar

We’re pleased to announce that the Research Forum will take place this year as an online event. The Forum will still feature all the fantastic research the Trust and academic staff have completed in the previous year.

The Forum will also include research posters which will be judged by delegates ahead of the event and announced on the day. Winning posters will receive prizes awarded for 1st and 2nd places. More information about poster submissions will be announced shortly.

To register to attend please visit: https://forms.gle/ZSiXUeavZkRyKRAY6