International Journal of Population Data Science

Journal Website: www.ijpds.org

Transparency in the existence, use, and output of a mental health data resource: a descriptive paper from the National Institute for Health and Care Research (NIHR) Maudsley Biomedical Research Centre (BRC) Clinical Record Interactive Search (CRIS) Platform

Amelia Jewell[1,*], Matthew Broadbent[1], Claire Delaney-Pope[1], Megan Pritchard[1], Hannah Woods[1], and Robert Stewart[1,2]

Submission History

Submitted:	15/11/2024
Accepted:	12/03/2025
Published:	10/04/2024

[1] South London and Maudsley NHS Foundation Trust, London, UK
[2] Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK

Abstract

Background
Transparency in the use of routinely collected mental health data for research is essential in maintaining public support and trust, as well as for supporting the sharing of information and data resources amongst the academic community. The National Institute for Health and Care Research (NIHR) Maudsley Biomedical Research Centre (BRC) Clinical Records Interactive Search (CRIS) enables a case register of deidentified mental health records from the South London and Maudsley NHS Foundation Trust (SLaM). CRIS supports mental health research across the lifespan from children and adolescents to older adults.

Aim
This paper aims to describe the activities which contribute to ensuring that transparency is maintained throughout the journey of data in CRIS: from data collection, through application in research, to dissemination of findings.

Approach
A communications plan is in place to support Patient and Public Involvement (PPI) and transparency initiatives for all CRIS stakeholders, including patients and carers, academic users, and the general public. Activities can be divided into three categories of transparency: existence, use, and output.

Discussion
There are challenges to maintaining transparency, including ensuring that activities are varied enough to reach all stakeholders, including harder to reach groups, and presenting information in a way that is appropriate for the relevant audience. However, greater transparency has led to more opportunities for researchers to engage with patients and the CRIS model is widely accepted by patients.

Conclusion
This paper set out to describe CRIS communications and transparency activities. We believe the material covered will be of interest to other providers of routinely collected data for research.

Keywords
transparency; mental health; patient and public involvement; fair processing; clinical record interactive search; CRIS

*Corresponding Author:
Email Address: amelia.jewell@slam.nhs.uk (Amelia Jewell)

https://doi.org/10.23889/ijpds.v10i2.2945

Introduction

Routinely collected mental health data from electronic patient records offer an important research asset which has improved our knowledge of mental healthcare interventions and their outcomes and has helped to solve challenging problems. For example, studies using routinely collected mental health data have helped to identify inequalities in treatment [1], support service planning [2], inform clinical practice [3], and support research into population mental health [4].

Historically, mental health records have been considered particularly sensitive by the general public [5, 6] with previous research reporting that mental health services users were more comfortable with their physical health data being shared for research purposes than their mental health data [7]. Despite this, more recent studies have shown that mental health patients are generally willing and positive about data sharing for mental health research purposes [8, 9] perhaps reflecting a change in attitude towards mental health research.

Transparency in the use of health data for research is crucial to public acceptance. Previous reports have found that communication is key to building public trust and the public are generally more positive towards the use of health data for medical research when informed about what medical research entails [10]. A 2016 systematic review of studies examining public attitudes towards the sharing of health data for research found that those studies which provided participants with opportunities to learn more about current or planned practices had greater support and acceptance as well as less concern about the research use of data [11].

Transparency in the use of data is also a legal requirement of the United Kingdom (UK) General Data Protection Regulations (GDPR) 2018. Specifically, organisations are required to tell people about how they are using their data to ensure that people are aware of when and how the organisation in question is using their personal information and for what purpose [12]. Extending beyond these legal requirements, organisations who are sharing data for research purposes also have a responsibility to meet societal expectations regarding use of the data; this is known as the 'social license' [13].

Transparency is also relevant to the users of data resources. Despite the clear benefits of using routinely collected health data for research, researchers can face barriers in access and utility which lead to inefficiencies and delays [14]. Transparency can help to remove some of these barriers and support the sharing of information and data resources amongst the academic community. One method to support transparency is through adoption of the FAIR principles which were developed to help improve the Findability, Accessibility, Interoperability, and Reusability of digital resources, including research databases [15].

It is clear that transparency in the use of data can have a sizeable positive impact, not only on the organisations providing access to data but also on those whose data is included in the system, and on the researchers and academics who use the data. In this article, we describe how transparency is incorporated from data collection through to dissemination in a large mental health case register based in southeast London.

Setting

The National Institute for Health and Care Research (NIHR) Maudsley Biomedical Research Centre (BRC) Clinical Record Interactive Search (CRIS) system, described previously in detail [16, 17], is a deidentified case register of electronic medical records for mental health patients from the South London and Maudsley National Health Service (NHS) Foundation Trust (SLaM). SLaM is one of the largest providers of secondary mental health care in Europe, providing mental health services predominately for the London boroughs of Lambeth, Southwark, Croydon, and Lewisham, as well as some national specialist services.

CRIS contains data from both structured fields, such as diagnoses and referrals, and unstructured free text fields, such as letters and clinical notes, within the medical record. Natural Language Processing (NLP) techniques have been evaluated and applied within CRIS for extracting information from unstructured data [16, 18]. Records from CRIS have also been linked to several external databases including the Department for Education's (DfE) National Pupil Database (NPD) [19], benefits and employment data from the Department for Work and Pensions (DWP) [20], acute hospital data from Hospital Episode Statistics (HES) [21], and the 2011 UK census [22].

The CRIS service, which supports the infrastructure and extraction of project-specific data, is managed by a dedicated team within SLaM. All use of CRIS is governed by the CRIS Security Model which is managed by a patient-led Oversight Committee [17, 23, 24]. The CRIS Oversight Committee review and approve all applications to use CRIS and includes representation from SLaM patients, Child and Adolescent Mental Health Services (CAMHS), the SLaM Caldicott Committee, and Research and Development (R&D). Since its launch in 2007, CRIS has supported over 380 research publications across the spectrum of mental health disorders, from childhood to older adults.

Transparency has been a founding principle of CRIS right from its inception, with Patient and Public Involvement (PPI) forming an integral part of the development and informing the original CRIS build in parallel with the technical developments [17]. This has continued throughout the past 17 years of CRIS with a comprehensive communications plan that aims to target all CRIS stakeholders. This communications plan is an explicit component of the CRIS Security Model and is overseen by the CRIS Oversight Committee. CRIS communications activities can be divided into three specific areas of transparency designed to cover the journey of information from data collection through to research outputs: Transparency in Existence, Transparency in Use, and Transparency in Output.

Who is a stakeholder?

We consider there to be four main categories of CRIS stakeholder: (1) those whose data is contained in the system, namely SLaM patients, (2) those who care for SLaM patients, (3) those who use the system for research, audits, and service evaluations including academic researchers and NHS staff, and (4) the general public. In terms of prioritisation, SLaM patients and carers are considered the first priority for CRIS

communications activities, this is to ensure that SLaM is meeting transparency requirements under the UK GDPR 2018.

Transparency in existence

Below we describe the activities undertaken to ensure that CRIS stakeholders are aware of the existence of CRIS. These activities help to make sure that SLaM meet the GDPR requirement of fair processing and are particularly important in relation to SLaM patients and carers who have the right to opt-out of their data being included in CRIS.

Leaflets and posters

SLaM has produced leaflets and posters targeting patients and the public to inform them of CRIS activity, including a CAMHS leaflet designed specifically for young people and their carers. These are displayed in SLaM waiting areas and team bases and represent the first point of contact that many patients will have with CRIS. This publicity material explains the purpose of processing deidentified clinical data for research and provides information on how people can find out more about CRIS, including how it has been used in data linkages. In 2023, the CRIS Team in collaboration with a mental health service user and the CRIS Oversight Committee undertook a project to update and redesign the leaflets and poster. The updated material includes new features such as a QR code to enable service users to more easily access further information on CRIS.

The CRIS leaflets and poster are one of several mandatory communication materials which SLaM services are required to display. Audits by SLaM's Information Governance (IG) Team ensure that services are displaying the required materials appropriately. Leaflets and posters are translated or produced in large print as required.

Fair processing notice

To comply with Articles 13 and 14 of the UK GDPR 2018, SLaM publishes a privacy notice [25] which includes concise information on how personal data are used within SLaM. This privacy notice includes information on CRIS and how health data are used for research as well as contact details for patients who wish to opt-out of their data being used within CRIS.

CRIS website

The CRIS webpages on the NIHR Maudsley BRC website [26] aim to be the main source of information for SLaM patients, academics, SLaM staff, and the general public who would like to find out more about CRIS. The webpages contain information about the history of CRIS, the CRIS Team, outputs from CRIS research such as publications, CRIS data linkages, and NLP algorithms as a resource. It is also a place to find out how to contact the CRIS Team and get involved with CRIS work, as well as information on opting out for SLaM service-users who do not want their information included in CRIS. The CRIS webpages are also the main source of information available to academic users prior to meeting with a member of the CRIS Team and is a large component of the wider CRIS communications plan which aims to ensure that all potential CRIS stakeholders can access relevant information about CRIS in several different formats.

In 2023, SLaM was awarded a grant from Health Data Research UK (HDR UK) to undertake a website review project to update the website in order to better meet the HDR UK Transparency Standards [27]. The Transparency Standards were co-developed by the Pan-UK Data Governance Steering Group and HDR UK's Public Advisory Board, with the aim of improving the transparency of processes for accessing health data for research. These standards were designed to guide best practice for transparency around how data are accessed and the information available to researchers and members of the public. This includes recommendations around transparency of application processes and criteria, website navigation, appropriate use of language based on target audience, and improving how organisations communicate the impact of health data research to improve and save lives.

The project involved both a lay review of the website conducted with five adult mental health service users, both patients and carers, as well as an academic review by two early career researchers. The review suggested several improvements to the website, such as adding more visual content, improving website navigation, and making the text and design more accessible. Feedback was reviewed and compared against the Transparency Standards. Changes were then made to webpages, including updating images, adding additional information, and making accessibility changes. Patient consultees were sent a further online questionnaire to provide feedback on the updated pages which was positive [28].

Drop-In sessions

The CRIS Team holds regular drop-in sessions designed for anyone who would like to find out more about CRIS, this includes both academic users and SLaM patients. These sessions are widely publicised via the CRIS website as well as through SLaM, NIHR Maudsley BRC, and Institute of Psychiatry, Psychology and Neuroscience (IOPPN), King's College London (KCL) communications channels. Including, for example, the weekly SLaM staff e-newsletter, NIHR Maudsley BRC social media channels, the CRIS newsletter, and physical posters.

Presentations

Since initial development, CRIS has been presented at many different events, aimed at all CRIS stakeholders. Examples include the annual SLaM staff conference, department-specific patient and carer groups, and department-specific clinical teams as requested. We continue to seek opportunities to present CRIS and discuss our work through various SLaM and NIHR Maudsley BRC events and meetings.

FAIR principles: findability and accessibility

Guided by the FAIR principles [15] to support the findability of CRIS as a resource, CRIS is included in the Catalogue of Mental Health Measures [29]. Designed to provide easy access to information about the mental health measures included

in British cohort and longitudinal studies, the Catalogue of Mental Health Measures aims to facilitate mental health research by maximising the use of existing data. Further to this, the Catalogue also interfaces with the HDR UK Innovation Gateway [30]. Established in 2020, the Gateway acts as a common entry point for researchers to discover and request access to UK health-related datasets.

Due to the strict governance surrounding the use of CRIS [17], data cannot be shared via open access repositories. Therefore, to support the accessibility of the data, the CRIS Team have produced guidance to support researchers with applying to use and accessing CRIS data. To ensure that the process for obtaining access is transparent, the link to the online application form and guidance notes, as well as a detailed 'Welcome to CRIS Guide' are made available via the public website on a dedicated Information for Researchers page [31]. The CRIS Security Model is also made available, this details the process by which CRIS applications are reviewed and approved by the patient-led CRIS Oversight Committee [24].

Transparency in use

The activities described below demonstrate how we ensure that CRIS stakeholders are aware of what the data in CRIS are used for as well as providing opportunities to provide input on how CRIS data are used.

Data use registry

All projects approved by the patient-led CRIS Oversight Committee are publicly available to view via the CRIS website [32]. The CRIS projects database includes the name of the lead applicant, the project title, lay summary, and approval date. Users can search on any of these fields to explore what research is being conducted using CRIS.

Transparency with commercial partnerships

The use of health data by commercial agencies is considered particularly controversial, in part due to the lower levels of trust that the public has in the private sector in comparison with public section organisations [11]. The potential use of CRIS in commercial partnerships is included in the CRIS information leaflet and all existing use of CRIS in commercial partnerships is transparent and documented in detail on the CRIS website [33]. For industry partnerships, the preferred protocol has been for data to be accessed by university or SLaM academic staff and the findings generated according to the specifications of the commercial partner, with no direct access to data by employees of the commercial partners themselves. An example of the type of project conducted using CRIS in a commercial partnership includes the real-world evaluation of the effectiveness of existing practice [34]. The above model whereby data is accessed and analysed by academic staff helps to maintain the independence of the results as well as ensuring that projects meet the conditions of the CRIS Security Model [17] and there have been no concerns raised or complaints to date.

Patient and carer involvement groups

PPI groups have been set up to support the ongoing use of CRIS and to provide advice and recommendations for projects using CRIS data. The Data Linkage Service User and Carer Advisory Group (DL-SUCAG) provides advice and feedback to researchers conducting projects involving data linkage [35]. Launched in January 2024, the Clinical Informatics Service (CIS) Advisory Group aims to identify the priorities of SLaM patients and carers for how clinical health record data should be used for research and informing patient care as well as advising on NLP development and application. The CRIS for Dementia Service User & Carer Advisory Group (C4D-SUCAG) ensures that dementia research conducted using CRIS is led by the concerns identified by people with dementia and their families. The CRIS PPI groups facilitate meaningful collaboration between SLaM patients and the researchers using CRIS data and an evaluation of the DL-SUCAG in 2019 found that both researchers and patients valued the experience of attending the group.

Data linkages

Targeted PPI relating to specific data linkages with CRIS is also undertaken. A recent example includes a podcast series highlighting the data linkage between CRIS and the 2011 UK Census data from the Office for National Statistics (ONS) [22]. The four-part series focusing on the data linkage and initial findings from the study as well as discussions around tackling systemic mental health inequalities and the future possibilities of mental health data, is widely available online [36] as well as on all major podcasting applications, including Apple Podcasts and Spotify.

Another example of transparency activities related to data linkage includes the project-specific leaflets and poster developed for the linkage between CRIS and the HIV and AIDS Reporting System (HARS) [37]. In collaboration with clinical colleagues, these leaflets were distributed to specific teams within SLaM who specifically support patients with HIV or who are more likely to come in to contact with patients with HIV. The distribution of the leaflets led to greater awareness of the research project which in turn led to further transparency opportunities including a presentation to both patients and clinical staff at an event to celebrate National HIV Testing Week.

Transparency in output

Below we describe the transparency activities which support the dissemination of findings from CRIS research.

Journal publications

A list of all publications resulting from CRIS projects is publicly available on the CRIS website [38]. Researchers publishing data from CRIS are encouraged to do so in Open Access journals or to save the final version in an Open Access repository so that they are accessible to a wider audience.

CRIS academic sessions

An academic seminar is held monthly where CRIS researchers are invited to present their work. Sessions are open to all and are advertised to both CRIS academic users [31] and SLaM patients and the public [39] via the CRIS website. These sessions are held in a hybrid format to enable attendance both virtually and in person.

Video campaign

A recent communications project saw researchers discussing their CRIS research as part of a video campaign. The six CRIS Research Insights videos [40] showcase some of the work being carried out by academics using CRIS. The launch of the videos in May 2024, supported by the NIHR Maudsley BRC Communications Team, included a comprehensive social media campaign across Facebook, X (formally Twitter), and LinkedIn. The campaign led to 11,300 impressions and 305 engagements on X, and 7,000 impressions and 2,600 video views on LinkedIn. In total, the social media campaign resulted in an additional 1,600 visits to the CRIS webpages.

Newsletter

Launched in March 2024, the CRIS newsletter is published every quarter and sent to all CRIS academic users as well as individuals who have chosen to sign up through the link on the public CRIS website. It contains information on recent CRIS updates as well as highlighting important CRIS research findings and news. The newsletter is currently delivered to over 550 email addresses and the second edition, published in July 2024, was opened by 206 (37%) recipients and links within the newsletter were clicked by 28 (7%) recipients.

FAIR principles: interoperability and reusability

To support the interoperability and reusability of CRIS data, all data extractions conducted by the CRIS Team are done according to project-specific data extraction specifications. These specifications define the cohort of interest and the output variables required for each project. Although one of the largest mental health Trusts in Europe, SLaM's catchment area only covers southeast London and limited national services, it is therefore important that findings from CRIS studies can be replicated at other sites to ensure reliability and generalisability of the results. Despite different mental health Trusts using different electronic patient record systems, meaning that code to extract data cannot always practically be applied to other sites, the data extraction specifications can be shared to enable equivalent datasets to be extracted across different systems. An example of this in practice was a project conducted during the COVID-19 pandemic where equivalent data were extracted across ten different UK mental health service providers which found that mental health services underwent profound changes during the first national lockdown beginning in March 2020 [4]. Other examples of multi-site collaborative research include investigations of crisis interventions to prevent readmission to acute mental healthcare [41], ethnic group differences in characteristics at dementia diagnosis [42], clozapine side effects [43], crisis presentations associated with social media exposures [44], antidepressant pharmacotherapy and dementia progression [45], and a recent estimate of demand for future Alzheimer's disease therapies [46].

To further support reusability, a Cloud service has been developed to enable the sharing of NLP applications developed using CRIS with other mental health Trusts. The Mental Health Text Analytics Cloud (MH-TAC) is a prototype cloud-based platform set up within the SLaM infrastructure that allows other mental health Trusts to upload text files into secure domains where they can be processed using previously developed and validated NLP algorithms. The NLP-derived meta-data are then returned to users.

Discussion

This paper sets out to describe the activities undertaken by the NIHR Maudsley BRC CRIS Team to ensure that transparency is maintained throughout the journey of data in CRIS. This transparency enables CRIS to both maintain public acceptance as a data resource and meet the necessary GDPR requirements as well as supporting academic users who wish to use the data.

Patient and public involvement has been an integral part of the development of CRIS, right from its inception [17]. The CRIS Oversight Committee, which reviews all applications to use the data and governs the CRIS Security Model, is chaired by a patient. This inclusion of patients in the governance of CRIS has been identified as an important component of the acceptance of the SLaM CRIS model as reported by Adanijo et al., (2021) in their qualitative study of mental health patients' views on acceptable data sharing [7].

Challenges and lessons learned

There are four categories of CRIS stakeholder which CRIS transparency activities aim to target: SLaM patients, carers, users of the resource, and the general public. One of the main challenges of ensuring comprehensive transparency is ensuring that communications activities are varied enough to reach these diverse groups of stakeholders.

With regards to patients and carers specifically, it can be challenging targeting harder-to-reach groups; this is particularly important as a major advantage of health records databases is that they provide better representation for these populations than traditional recruitment-based (and, hence, inevitably selected) research cohorts. SLaM services support patients throughout the lifespan, including patients with varying levels of capacity. CRIS communication activities need to ensure that they reach all these different groups. Current communication activities are varied to try and reach as many people as possible and include both physical leaflets and posters as well as online resources such as the CRIS webpages and video campaign. Regardless, we acknowledge that despite our best efforts our communications activities may not reach all patient groups.

Through the recent review of the CRIS webpages [28], we found that different people like to take in information in different formats, for example text, pictures, or videos. Throughout the project, there were challenges involved in designing a website that was informative to both lay public

readers and potential research users. We learnt that providing dedicated pages for patients and academic users can help to tailor relevant information to different stakeholders.

Data science is challenging, and reports suggest that the general public have limited knowledge about data and the regulations surrounding it [47]. It can therefore be difficult to obtain meaningful engagement from patients and the public without requiring further training. Although, it can be challenging to find a balance between increasing awareness without coercing viewpoints. However, in our experience with our patient and carer advisory groups, providing a basic level of training enabled members to engage effectively and was well received by group members [35]. We have also engaged with patients and carers in the development of our leaflets, posters, and website content to ensure that the content is pitched at a level that is understandable by the general public. Where possible we have also tailored content, for example by having a CAMHS specific CRIS leaflet.

Working with data from electronic medical records can reduce researchers' opportunities to engage with participants compared to what would be built into projects involving traditional recruitment and data collection. The transparency activities across CRIS, such as the PPI groups and engagement with the patient-led CRIS Oversight Committee, give researchers the opportunity to engage with patients and receive feedback on projects which can have a valuable impact on their research whilst also supporting transparency in the use of the CRIS data resource.

Conclusion

This paper describes the activities undertaken at the NIHR Maudsley BRC CRIS mental health case register, to incorporate transparency along the path from data collection to data use and through to dissemination of research findings. We believe the material presented in this paper will be of use to other data providers looking to foster transparency in their data resources.

Acknowledgements

CRIS is funded by the National Institute for Health and Care Research (NIHR) Maudsley Biomedical Research Centre (BRC) at South London and Maudsley NHS Foundation Trust (SLaM) and King's College London (KCL). RS is additionally part-funded by: i) the NIHR Applied Research Collaboration South London (NIHR ARC South London) at King's College Hospital NHS Foundation Trust; ii) UKRI – Medical Research Council through the DATAMIND HDR UK Mental Health Data Hub (MRC reference: MR/W014386); iii) the UK Prevention Research Partnership (Violence, Health and Society; MR-VO49879/1), an initiative funded by UK Research and Innovation Councils, the Department of Health and Social Care (England) and the UK devolved administrations, and leading health research charities. The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

The authors would like to acknowledge the contribution of the members of the three CRIS Service User Advisory Groups: The Data Linkage Service User and Carer Advisory Group (DL-SUCAG), the Clinical Informatics Service (CIS) Advisory Group, and the CRIS for Dementia Service User and Carer Advisory Group (C4D-SUCAG). As well as the support of individual teams within SLaM who support the CRIS service and infrastructure, including the CRIS Team, Information Governance Team, and SLaM Digital Services. We would also like to acknowledge the NIHR Maudsley BRC Communications and SLaM Communications Teams for their support with executing CRIS communications and transparency activities.

Statement of conflict of interest

All authors have substantive (AJ, MB, CDP, MP, HW) or honorary (RS) contracts with the South London and Maudsley NHS Foundation Trust which hosts the CRIS resource described here. RS declares research support received in the last 3 years from GSK and Takeda.

Ethics statement

This paper reports no original data. CRIS has ethics approval as a database for secondary research from South Central – Oxford C Research Ethics Committee (REC Reference: 23/SC/0257).

Data availability statement

No data was created or used in this paper.

References

1. Woodhead A, Ashworth M, Broadbent M, Callard F, Hotopf M, Schofield P, et al. Cardiovascular disease treatment among patients with severe mental illness: a data linkage study between primary and secondary care. *British Journal of General Practice*. 2016;e374. https://doi.org/10.3399/bjgp16X685189

2. Laurell AAS, Venkataraman AV, Schmidt T, Montagnese M, Mueller C, Stewart R, et al. Estimating demand for potential disease-modifying therapies for Alzheimer's disease in the UK. *The British Journal of Psychiatry*. 2024;224:198–204. https://doi.org/10.1192/bjp.2023.166

3. Yang JC, Thygesen JH, Werbeloff N, Hayes JF, Osborn DPJ. Antipsychotic polypharmacy and adverse drug reactions among adults in a London mental health service, 2008–2018. *Psychological Medicine*. 2023; 53:4220–7. https://doi.org/10.1017/S0033291722000952

4. Bakolis I, Stewart R, Baldwin D, Beenstock J, Bibby P, Broadbent M, et al. Changes in daily mental health service use and mortality at the commencement and lifting of COVID-19 'lockdown' policy in 10 UK sites: a regression discontinuity in time design. *BMJ Open*. 2021;11:e049721. https://doi.org/10.1136/bmjopen-2021-049721

5. Robling MR, Hood K, Houston H, Pill R, Fay J, Evans HM. Public attitudes towards the use of primary care patient record data in medical research without consent: a qualitative study. *J Med Ethics*. 2004;30:104–109. https://doi.org/10.1136/jme.2003.005157

6. The Wellcome Trust. *Summary Report of Qualitative Research into Public Attitudes to Personal Data and Linking Personal Data*. 2013.

7. Adanijo A, McWilliams C, Wykes T, Jilka S. Investigating Mental Health Service User Opinions on Clinical Data Sharing: Qualitative Focus Group Study. *JMIR Mental Health*. 2021;8(9):e30596. https://doi.org/10.2196/30596

8. Kirkham EJ, Lawrie SM, Crompton CJ, Iveson MH, Jenkins ND, Goerdten J, et al. Experience of clinical services shapes attitudes to mental health data sharing: findings from a UK-wide survey. *BMC Public Health*. 2022;22:357. https://doi.org/10.1186/s12889-022-12694-z

9. Watson E, Fletcher-Watson S, Kirkham EJ. Views on sharing mental health data for research purposes: qualitative analysis of interviews with people with mental illness. *BMC Medical Ethics*. 2023;24:99. https://doi.org/10.1186/s12910-023-00961-6

10. Ipsos MORI. *The Use of Personal Health Information in Medical Research*. Medical Research Council. 2007.

11. Aitken M, Jorre JdS, Pagliari C, Jepson R, Cunningham-Burley S. Public responses to the sharing and linkage of health data for research purposes: a systematic review and thematic synthesis of qualitative studies. *BMC Medical Ethics*. 2016;17:73. https://doi.org/10.1186/s12910-016-0153-x

12. Information Commissioner's Office. *What is Transparency?* https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/transparency-in-health-and-social-care/what-is-transparency/#whatistransparency. [Accessed 7th October 2024].

13. Carter P, Laurie GT, Dixon-Woods M. The social licence for research: why care.data ran into trouble. *J Med Ethics*. 2015;41:404-9. https://doi.org/10.1136/medethics-2014-102374

14. Ford E, Boyd A, Bowles JKF, Havard A, Aldrige RW, Curcin V, et al. Our data, our society, our health: A vision for inclusive and transparent health data science in the United Kingdom and beyond. *Learning Health Systems*. 2019;3:e10191. https://doi.org/10.1002/lrh2.10191

15. Wilkinson MD, Dumontier M, Aalbersberg IJ, Appleton G, Axton M, Baak A, et al. The FAIR Guiding Principles for scientific data management and stewardship. *Scientific Data*. 2016;3:160018. https://doi.org/10.1038/sdata.2016.18

16. Perera G, Broadbent M, Callard F, Chang CK, Downs J, Dutta R, et al. Cohort profile of the South London and Maudsley NHS Foundation Trust Biomedical Research Centre (SLaM BRC) Case Register: current status and recent enhancement of an Electronic Mental Health Record-derived data resource. *BMJ Open*. 2016;6:e008721. https://doi.org/10.1136/bmjopen-2015-008721

17. Stewart R, Soremekun M, Perera G, Broadbent M, Callard F, Denis M, et al. The South London and Maudsley NHS Foundation Trust Biomedical Research Centre (SLAM BRC) case register: development and descriptive data. *BMC Psychiatry*. 2009;9:51. https://doi.org/10.1186/1471-244X-9-51

18. Maudsley Biomedical Research Centre (BRC). Natural Language Processing (NLP) Service. https://www.maudsleybrc.nihr.ac.uk/facilities/clinical-record-interactive-search-cris/cris-natural-language-processing/. [Accessed 23rd October 2024].

19. Downs J, Ford T, Stewart R, Epstein S, Shetty H, Little R, et al. An approach to linking education, social care and electronic health records for children and young people in South London: a linkage study of child and adolescent mental health service data. *BMJ Open*. 2019;9:e024355. https://doi.org/ 10.1136/bmjopen-2018-024355

20. Phillips A, Leal R, Jewell A, Madan I, Downs J, Broadbent M, et al. Cohort profile: working age adults accessing secondary mental health services in South London (UK) and benefits – a data linkage of electronic mental health records and benefits data. *International Journal of Population Data Science*. 2024;9:1:15. https://doi.org/10.23889/ijpds.v9i1.2377

21. Jewell A, Broadbent M, Hayes RD, Gilbert R, Stewart R, Downs J. Impact of matching error on linked mortality outcome in a data linkage of secondary mental health data with Hospital Episode Statistics (HES) and mortality records in South East London: a cross-sectional study. *BMJ Open*. 2020:10:e035884. https://doi.org/10.1136/bmjopen-2019-035884

22. Cybulski L, Gray MacIntyre Chilman N, Jewell A, Dewey M, Hildersley R, Morgan C et al. Improving our understanding of the social determinants of mental health: A data linkage study of mental health records and the 2011 UK census. *BMJ Open*. 2023;14(1):e073582. https://doi.org/10.1136/bmjopen-2023-073582

23. Fernandes AC, Cloete D, Broadbent MTM, Hayes RD, Chang C-K, Jackson RG, et al. Development and evaluation of a de-identification procedure for a case register sourced from mental health electronic records. *BMC Medical Informatics and Decision Making*. 2013;13:71. https://doi.org/10.1186/1472-6947-13-71

24. Maudsley Biomedical Research Centre (BRC). Clinical Record Interactive Search (CRIS) Operational Security model. www.maudsleybrc.nihr.ac.uk/media/573352/cris_

security_model_active.pdf. [Accessed 23rd October 2024].

25. South London and Maudsley NHS Foundation Trust. Personal information and data protection. https://slam.nhs.uk/personal-information-gdpr. [Accessed 9th October 2024].

26. Maudsley Biomedical Research Centre (BRC). Clinical Record Interactive Search (CRIS). www.maudsleybrc.nihr.ac.uk/facilities/clinical-record-interactive-search-cris/. [Accessed 9th October 2024].

27. Macaulay Y, UK Health Data Research Alliance, Pan-UK Data Governance Steering Group, HDR UK Public Advisory Board, Five Safes Action Force. *Pan-UK Data Governance Steering Group Data Access Transparency Standards*. https://zenodo.org/records/8262453. [Accessed 7th October 2024].

28. Jewell A, Woods H, Morrow L, Booth A, Davenport F, Stewart R. Lay review of the South London and Maudsley NHS Foundation Trust's (SLaM) Clinical Records Interactive Search (CRIS) system website to better meet UK Heath Data Research Alliance Transparency Standards. *International Journal of Population Data Science*. 2023;9(3). https://doi.org/10.23889/ijpds.v9i3.2453

29. King's College London. Catalogue of Mental Health Measures. https://www.cataloguementalhealth.ac.uk/. [Accessed 8th October 2024].

30. Health Data Research (HDR) UK. Innovation Gateway. https://www.healthdatagateway.org/. [Accessed 23rd October 2024].

31. Maudsley Biomedical Research Centre (BRC). Information for Researchers. https://maudsleybrc.nihr.ac.uk/facilities/clinical-record-interactive-search-cris/information-for-researchers/. [Accessed 9th October 2024].

32. Maudsley Biomedical Research Centre (BRC). CRIS Projects. www.maudsleybrc.nihr.ac.uk/facilities/clinical-record-interactive-search-cris/cris-projects/. [Accessed 9th October 2024].

33. Maudsley Biomedical Research Centre (BRC). Commercial Partnerships. https://maudsleybrc.nihr.ac.uk/facilities/clinical-record-interactive-search-cris/cris-use-in-commercial-partnerships/. [Accessed 9th October 2024].

34. Kadra-Scalzo G, Ahn D, Bird A, Broadbent M, Chang C-K, Pritchard M, et al. Mental healthcare utilisation by patients before and after receiving paliperidone palmitate treatment: mirror image analyses. *BMJ Open*. 2022;12:4. https://doi.org/10.1136/bmjopen-2021-051567

35. Jewell A, Pritchard M, Barrett K, Green P, Markham S, McKenzie S, et al. The Maudsley Biomedical Research Centre (BRC) data linkage service user and carer advisory group: creating and sustaining a successful patient and public involvement group to guide research in a complex area. *Research Involvement and Engagement*. 2019;5:2. https://doi.org/10.1186/s40900-019-0152-4

36. King's College London. The Big Ideas – Special Series: Our Sick Society. https://soundcloud.com/oursicksociety/sets/the-big-ideas-special-series. [Accessed 9th October 2024].

37. Heslin M, Jewell A, Croxford S, Chau C, Smith S, Pittrof R, et al. Prevalence of HIV in mental health service users: a retrospective cohort study. *BMJ Open*. 2023;13:e067337. https://doi.org/10.1136/bmjopen-2022-067337

38. Maudsley Biomedical Research Centre (BRC). Clinical Record Interactive Search (CRIS) Publications. https://maudsleybrc.nihr.ac.uk/facilities/clinical-record-interactive-search-cris/cris-publications/. [Accessed 9th October 2024].

39. Maudsley Biomedical Research Centre (BRC). Information for Patients and the Public. https://maudsleybrc.nihr.ac.uk/facilities/clinical-record-interactive-search-cris/information-for-patients-and-the-public/. [Accessed 9th October 2024].

40. Maudsley Biomedical Research Centre (BRC). Watch: CRIS Research Insights. https://maudsleybrc.nihr.ac.uk/facilities/clinical-record-interactive-search-cris/videos-research-insights/. [Accessed 9th October 2024].

41. Werbeloff N, Chang C-K, Broadbent M, Hayes JF, Stewart R, Osborn DPJ. Admission to acute mental health services following contact with crisis resolution and home treatment teams. *Lancet Psychiatry*. 2017. 4:49-56. https://doi.org/10.1016/S2215-0366(16)30416-3

42. Mukadam N, Lewis G, Mueller C, Werbeloff N, Stewart R, Livingston G. Ethnic differences in cognition and age in people diagnosed with dementia: a study of electronic health records in two large mental healthcare providers. *International Journal of Geriatric Psychiatry*. 2019. 34:504-10. https://doi.org/ 10.1002/gps.5046

43. Iqbal E, Govind R, Romero A, Dzahini O, Broadbent M, Stewart R. et al. The side effect profile of clozapine in real world data of three large mental health hospitals. *PLoS One*. 2020. 15;e0243437. https://doi.org/10.1371/journal.pone.0243437

44. Kolliakou A, Bakolis I, Chandran D, Derczynski L, Werbeloff N, Osborn DPJ, et al. Mental health-related conversations on social media and crisis episodes: a time-series regression analysis. *Scientific Reports*. 2020. 10:1342. https://doi.org/10.1038/s41598-020-57835-9

45. Sommerlad A, Werbeloff N, Perera G, Smith T, Costello H, Mueller C, et al. Effect of trazodone on cognitive

decline in people with dementia: cohort study using UK routinely collected data. *International Journal of Geriatric Psychiatry*. 2021. 37;1. https://doi.org/10.1002/gps.5625

46. Laurell AAS, Venkataraman AV, Schmidt T, Montagnese M, Mueller C, Stewart R, et al. Estimating demand for potential disease-modifying therapies for Alzheimer's disease in the UK. *British Journal of Psychiatry*. 2024. 224;6:198-204. https://doi.org/10.1192/bjp.2023.166

47. Ipsos MORI. The One-Way Mirror: *Public attitudes to commercial access to health data*. Wellcome Trust. 2016.