

International Review of Mental Health Experience Surveys



### **About the National Care Experience Programme**

The National Care Experience Programme seeks to improve the quality of health and social care services in Ireland by asking people about their experiences of care and acting on their feedback. The National Care Experience Programme is a joint initiative by the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health.

The National Care Experience Programme has a suite of surveys that capture the experiences of people using our services. The programme implements the annual National Inpatient Experience Survey, the National Maternity Experience Survey, the National Maternity Bereavement Experience Survey, the National Nursing Home Experience Survey, and the National End of Life Survey.

The surveys aim to learn from people's feedback about the care received in health and social care services to find out what is working well, and what needs to be improved.

A National Care Experience Programme Survey Hub is available to provide support, guidance, information and resources to assist providers to develop, conduct and analyse their own surveys, and act upon the findings.



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## **1. Introduction**

Patient-centred care can be described as care that places value on a patient's preferences, opinion and values; and it combines a biopsychosocial and biomedical perspective to address their health needs with the aim of building a strong relationship between the patient and healthcare provider.<sup>(1)</sup> Furthermore, patient-centred care has been widely recognised as a core component of quality healthcare and measure of care quality and health system performance.<sup>(2)</sup>

Measuring patient-centred care and care quality is based on the collection of patient experience data. This is because accurately evaluating patient experience data helps us to understand the complex aspects of quality care with facts. Collecting data on lived experiences of patients allows us to compare hospital performance, monitor the efficacy of interventions and establish areas for improvement in health and social care services.<sup>(3)</sup> Therefore, patient experience is described as one of the three pillars<sup>1</sup> of quality in healthcare.<sup>(4)</sup>

Surveys have been widely used as a core method for obtaining patient experience data as they provide healthcare organisations with information regarding care, that are of specific interest to patients.<sup>(5)</sup> Surveys which capture experiences of those who use healthcare services have been adopted at a national level by many countries. This is due to the many benefits that have been gained by stakeholders including service providers, people who use the services, the public and national policy developers and regulators. For example, patient experience surveys can result in improved communication, and patient health outcomes, improved efficiency for healthcare professionals, and enhance strategic decision making.<sup>(1,6)</sup> Additionally, these surveys provide an opportunity for patients and people who use services to be involved in decision-making in their own care and co-partners in improving the quality of healthcare services.

For healthcare providers, the data collected by care experience surveys helps to identify areas for improvement, provide assurance in the care being provided, and benchmark care experience both nationally and internationally. As care experience surveys are tools which inform healthcare management of the quality and safety of care provided, they drive accountability across the healthcare system.

Furthermore, they provide legislators with definitive data to inform policy development and implementation. They also inform the development of national care standards, in addition to monitoring and regulation programmes for services.

In Ireland, national health policy highlights the importance of engaging with people who use health and social care services and capturing their care experiences to inform quality improvements in healthcare.

<sup>&</sup>lt;sup>1</sup> Three pillars refer to safety, clinical effectiveness and patient experience.



The Department of Health's Statement of Strategy 2023-2025 commits to improving health and wellbeing for all and delivering the right care in the right place at the right time.<sup>(7)</sup>

It plans for the implementation of national strategies, which are underpinned by the engagement of people that use health and social care services, for example Sharing the Vision: A Mental Health Policy for Everyone, Implementation Plan 2022-2024<sup>(8)</sup> and the National Cancer Strategy 2016-2026.<sup>(9)</sup>Similarly, Sláintecare, the 10-year, cross-political party strategy for healthcare and health policy in Ireland, advocates that "the voices of current service users and citizens must therefore be at the heart of healthcare reform, and success will be judged in terms of patient experience and outcomes and the overall health of our population".<sup>(10)</sup> Sláintecare explicitly sets out the development and expansion of systems to capture patient experience.<sup>(11)</sup>

In Ireland, the inaugural National Inpatient Experience Survey was successfully conducted in May 2017, when over 13,000 patients, representing a 51% response rate, shared their experience of care in Ireland's public acute hospitals.<sup>(12)</sup> The findings helped to inform national and hospital-level quality improvements across the acute inpatient hospital sector.

At the national level, the Health Service Executive (HSE) established an Oversight Group to review the findings of the National Inpatient Experience Survey and to develop a systematic plan for improving patient experience across acute hospitals. This led to the establishment of the National Healthcare Communication Programme. At local level, every hospital designed a quality improvement plan to address the findings.<sup>(13)</sup>

The National Care Experience Programme (NCEP) is a partnership programme between the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health. Initially established to run the National Inpatient Experience Survey and upon its success, expanded the programme to capture the experiences of maternity, end-of-life care, nursing homes, mental health and those who use cancer care services.

#### National context of mental health surveys in Ireland

The current national mental health policy 'Sharing the Vision (StV) – A Mental Health Policy for Everyone' published in 2020 serves as a policy framework to build upon the success of its predecessor A Vision for Change. StV provides a structure for building a responsive and up to date mental health service that fits the needs of people in Ireland for the next 10 years. As part of the implementation strategy for this policy framework, one of the recommendations (Domain: Accountability and Continuous Improvement - Recommendation 78) proposed that an independent national mental health service experience survey should be developed and



considered for inclusion under the National Care Experience Programme for driving accountability and continuous improvement. As such, the National Care Experience Programme<sup>(8)</sup> is developing a national mental health experience survey to understand the care experiences of people who use mental health services in Ireland.

It is important to acknowledge that the global outbreak of COVID-19 in brought a focus to population mental health and created a significant burden on service needs and delivery. The deviation from normal everyday life required by lockdowns, isolation, and the death and loss of family and friends, impacted greatly on mental health and wellbeing as identified in the HSE Psychosocial Response to the COVID-19 Pandemic Report.<sup>(14)</sup>

#### **1.2 Aims and objectives**

The aim of this international review is to identify and analyse international experience and best practice with regard to the model and methodology employed to deliver a national survey of the experiences of those who have received mental health care. To date, there is no standardised national approach to capture the experience of care of those who have received mental health care in Ireland.

This report explores the model and methodology used in international jurisdictions to capture the experience of people who use services within mental health settings. Through identifying international best practice, this review will inform the National Care Experience Programme's optimal approach to implementing a national mental health experience survey in Ireland.

#### 1.3 Methodology

A scoping review of international literature on the development and implementation of a national mental health experience survey was conducted in the first instance. In defining the inclusion criteria for selecting countries and surveys, it was decided that access to technical and methodological documentation, key personnel and affiliation with reputable organisations and agencies would inform the review process.

Based on these criteria, four countries were selected from the review for inclusion in this document. It will outline the operational governance and reporting process employed in each survey.

#### **1.4 Structure**

This document presents a summary of the findings from the international review which was undertaken to inform the development of an appropriate model and methodology for a survey of people who use mental health services in Ireland.

The four international jurisdictions reviewed in detail in this report are:



- Australia
- Denmark
- Norway
- England.

Findings for this review were compiled from national documentation from each country and detailed discussions with key relevant personnel who were involved in the development and or management of mental health care experience surveys within each country. Appendix 1 lists the personnel who were consulted within each organisation.

Findings in relation to each of the four selected countries are presented in this report under the following headings:

- Objectives
- Governance arrangements
- Legislative requirements for data protection
- Ethical approval
- Communication
- The survey
- Survey methodology
- Outputs
- Impact

This review focuses on the model and methodology used in each jurisdiction, in particular:

- Operational perspectives and associated requirements, survey model and methodology, resources, governance structures, information governance, administration and implementation of the survey model.
- Administrative requirements, including communications and distribution of survey material and resources.
- Outputs and reporting structures, that is what is reported and in what format and how survey findings are used to improve care.

The specific survey question libraries are not reviewed in this document as they are evaluated as part of a separate process.

A summary table of the models and methodologies outlined in this report can be found in Appendix 2.



## 2. Summary of findings

A summary of findings on care experience surveys of people who use mental health services is set out below.

#### 2.1 Objectives

The overall objective of conducting a survey in each of the countries reviewed was to listen to the collective voice of people who use services in order to evaluate the quality and standard of care provided in these settings. The survey findings are used to enhance accountability, inform policy and ultimately to improve the quality of care provided to residents.

#### 2.2 Governance arrangements

Governance arrangements for the surveys varied between countries. In all four countries, the surveys were overseen or coordinated by government or governmental bodies. For example, Norway and Denmark operated under a collaboration between the Ministry of Health and local regions. Australia's survey was managed by the Primary Health Networks but in collaboration with the Department of Health; and in England the survey was managed by the Picker institute<sup>2</sup> on behalf of the Care Quality Commission.<sup>3</sup>

Additionally, all counties emphasised the importance of having a structured systematic data collection methodology in place to understand the experiences of people who use services across mental health settings.

#### 2.3 Legislative requirements for data protection

The legislative requirements around data protection are a significant consideration for experience surveys for people who use services, largely due to the requirement of personal data to conduct and distribute a survey. Each of the four countries examined in this review had varying data sharing agreements in place with service providers. Each country followed their relevant national data privacy legislation. In addition to national laws, European based countries must also comply with General Data Protection Regulation (GDPR), for example, Denmark. Further, all countries ensured that data collected was anonymised and confidential.

Consent in all four surveys was informed and voluntary. In Australia, consent to receive the survey link was requested at the initial point of contact. However, in Norway and Denmark completion of the survey constitutes consent from the individual who uses the service.

<sup>&</sup>lt;sup>2</sup> Picker Institute are a leading healthcare charity who research patient and staff experience of care. They work with NHS trusts, government, charities, academia and commercial organisations.

<sup>&</sup>lt;sup>3</sup> The Care Quality Commission (CQC) is the independent regulator of health and social care services in England.



#### 2.4 Ethical approval

Ethical approval was not required for any of the four surveys reviewed. In the case of Australia, Norway and England the surveys did not require ethical approval as they were conducted for quality assurance purposes. The Danish survey did not require ethics approval as it is carried out for public interest.

#### **2.5 Communication**

Mental health surveys typically have low response rates which could be attributed to the shame and stigma associated with receiving this type of care. Therefore, the use of communication and promotional material is crucial to creating awareness of the surveys and increasing response rates. The communication strategies used throughout the surveys include:

- Establishing a contact person at hospital or service provider level, in health authorities and other institutions.
- Development of educational material to inform the contact person at hospital or service provider level, in clinical teams and general practitioners (GPs).
- Social media using platforms such as Twitter/X, LinkedIn, Facebook, and Instagram.
- Press release.
- Posters, animations and postcards.
- Video content for local level service providers.

#### 2.6 The survey Eligibility criteria

The eligibility criteria varied significantly across all four mental health surveys, with age and setting being factors that affect the inclusion criteria in some surveys. For example, the Australian and English surveys both looked at people who use mental health services in a community centre. However, in the UK eligible participants had to be at least 16 years of age and must have had one contact during the sample period and one other contact either before, during or after the sample period. On the other hand, Australia invites people who use services three months after care or at the point of discharge, whichever comes first, to participate in the survey.

The Norwegian survey only included all adult in patients who received specialised care in a psychiatric institution/unit and who are 18 years or over. Whilst, the Danish survey had different inclusion criteria which was dependent on the type of participant. For example, there were adult in-patient and out-patient surveys as well as two different surveys for children depending on their age group. Furthermore, surveys existed for relatives for inpatient and out-patient.

#### Question pool

An international library of validated questions is not available for mental health surveys as is the case for surveys of acute inpatient user care. Most surveys have



developed, tested and piloted their own questions or adopted some of those used in other surveys. Most surveys developed questions which covered the pathways of care.

Additionally, most surveys in this review included a number of demographic information question related to the person using the service completing the survey, including past mental health history, age and gender. The majority of surveys also included a short space for open-ended questions. These free texts comments allowed people who use services to express their opinion on other aspects of their care that may not have been included in the survey.

#### 2.7 Survey methodology Mode of contact

The mode of contacting eligible participants<sup>4</sup> to participate in the survey varied among all four countries included in the survey. In Denmark participants are identified through the national psychiatric registers and service users are invited to complete the surveys through their individual digital mail box. While in Australia people who use services are invited to take part by staff members which is followed up with an SMS link or an email invited the service user to complete the survey. Norway contacted participants using a 'staff referral' approach where participants were invited as close as possible to the time of discharge from care by staff members at the institution to take part in the survey. In Norway for example, institutions provided iPads, telephones and computers to aid participants with the survey.

However, in England the survey adopted a mixed mode approach where participants were initially invited to take part in the survey online via letters, with a paper questionnaire being sent out as follow up.

#### Mode of response

The majority of surveys in this review utilised an electronic and postal mode of response. In all Australia, Denmark and England, participants could respond to the survey online, through paper or could request to respond through telephone. However, in Norway participants could only respond electronically through their personal digital mailbox.

#### Frequency

<sup>&</sup>lt;sup>4</sup> Across the four countries reviewed, different terms are used to describe a person who engages with mental health services. These terms include 'patient', 'service user', 'eligible participants', 'consumers' or 'someone who uses the mental health services'. In various sections, different terms have been used in line with the language used in those jurisdictions. Where possible and to be consistent, concise and clear, the term 'people who use services' has mainly been selected for the purposes of this report.



There are different approaches used in the frequency of undertaking surveys of people who use mental health services. Since 2020, in Australia all consented consumers exiting the service or after three months of care, whichever comes first are surveyed. In Denmark since 2022, a monthly digital survey model is in place. In Norway, the survey is ongoing, people who use services are recruited to the national survey as close to the time of discharge as possible. While in England the Community Mental Health survey is carried out annually since 2003. In 2022, as part of the survey review process, the sampling period for the 2023 survey was altered from September to November (three months) to April and May (two months).

#### **Response rate**

The response rates of the surveys undertaken in the countries reviewed varied significantly and had a range from 20% to 70%. In Australia a 50% response rate is considered desirable.

Since 2022, a monthly digital survey model is in place in Denmark and response rates are not available for this model at the time of writing. However, the pre-digital survey model response rate was broken down into adult inpatient and outpatient. Adult In-patients were reported to have a response rate of 66% whilst, out-patient has a response rate of 61%.

For the Norwegian survey, the large national sample included responses from 70% of all in-patient units. Finally, in England there were a total of 14,770 responses (7,527 online responses and 7,052 paper responses) from people who received treatment for a mental health condition between 1 April and 31 May 2023, giving a 20% response rate.

#### 2.8 Outputs

The survey results are analysed and reported in each of the countries examined. In Australia, Denmark and Norway the results are published at a national, regional and unit/local level. In England, the survey results are published in benchmark reports for each individual trusts and it also shows how each trust compares to one another. The majority of the surveys reviewed utilised the data from the surveys to identify areas for improvement, formulate health policies and develop a plan for improvement of experience.

#### 2.9 Impacts

The requirement to act on findings of mental health surveys varied among the countries reviewed. The findings from the surveys were applied for to inform improvements in practice, policy, regulation and standards.

The clear benefits of conducting such surveys are acknowledged and they are regarded as highly significant for all stakeholders, including people who use services, their family, carer or support person, service provider organisations, regulators and policy-makers. This review indicates that there is a clear understanding around the



importance of conducting this type of survey in order to obtain invaluable insights from the collective voice of people who use mental health services to understand their lived experiences and to improve the care provided.



# Methodologies for international mental health experience surveys

## 3. Australia

**AUSTRALIA** – Head to Health Initial Intake Experience Survey and Head to Health Your Experience of Services (YES) Primary Health Networks Mental Health Survey.

#### Overview

The following review is of a specific area of mental health services based on the insights provided and the information shared by the experts we engaged with. The reviews focus was on the Head to Health Referral and Assessment Initial Experience survey and the Head to Health Your Experience of Service (YES) Primary Health Network (YES PHN)<sup>(15)</sup> survey carried out by North Western Melbourne Primary Health Network (NWMPHN) commissioned<sup>5</sup> primary mental health care providers. However, throughout Australia there are different surveys carried out in the area of mental healthcare for inpatient user, specialist, commissioned/community services and so on.

The North Western Melbourne Primary Health Network's (NWMPHN) catchment covers an area of 3,212 square kilometres. It is one of the most socially, culturally and economically diverse and complex regions in Australia and has a population of 1.9 million. Many individuals and groups within the region experience significant disadvantage, including low incomes, advanced age, poor education, homelessness, disability, mental health challenges and chronic disease. There are over 200 languages spoken in the region, with a significant proportion of non-English speaking residents.

#### 3.1 Background

Australia is made up of six states and two territories, New South Wales, Victoria, Queensland, Western Australia, South Australia, Tasmania, Northern Territory and Australia's Capital Territory with a population of in excess of 26 million. A National Study of Mental Health and Wellbeing was carried between 2020 and 2022. The findings from this report published in October 2023, identified that 4.3 million Australians aged 16–85 years had a 12-month history of a mental health disorder. Of these, 1.9 million (45.1%) saw a health professional for their mental health during the two-year time period.<sup>(16)</sup>

The 2021 report of the Royal Commission into Victoria's' Mental Health System.<sup>(17)</sup> in Australia reiterated the need for a major reform of the existing system and redesign of its mental health and wellbeing services to support and meet the diverse needs of

<sup>&</sup>lt;sup>5</sup>Commissioning refers to the ongoing process of planning, purchasing and monitoring of services to meet the needs of the local population.



'people living with mental illness or psychological distress, families, carers and supporters' moving towards a community-based model of care. The report acknowledged the severe pressure experienced by people, and placed on services during the bush fires of 2019-2020 along with the COVID-19 pandemic. The Commission set out 65 recommendations to transform Victoria's mental health system, to include new structures to support services, ensuring accessible treatment, care and support options, redesigning services to move from a crisis-driven model to a community-based one delivering worthwhile outcomes for people and drawing on people's lived experience of mental illness or psychological distress to support improvements.

In Australia, the National Safety and Quality Health Service Standards stipulate that health services have processes in place to seek regular feedback from people who use services, carers and families about their experience of care.<sup>(18)</sup> Substantial work has been undertaken over the years in Australia and internationally in all areas of health and social care to establish processes that regularly capture information on the perspectives of consumers and their carers about the health care they receive,<sup>(19)</sup> and to drive service quality improvement. (Standard 3 of the National Standards for Mental Health Services 2010).<sup>(20)</sup>

#### **Primary Health Networks**

The Australian Government established 31 Primary Health Networks (PHNs) across Australia as part of its mental health reform agenda in 2015.<sup>(21)</sup>

PHNs are independent, government funded organisations, set up to manage health regions and to streamline health services. PHNs operate as commissioning organisations and do not directly deliver clinical primary health or social care services. The work of the PHNs is overseen by a Board of Directors. PHNs manage their region in line with the needs of their community, based on consultation and guidance from community advisory committees and clinical councils, and in line with the health priorities of the Australian Government. Programme guidelines and a performance framework provide structure for the programme.<sup>(22)</sup>

The main objective of establishing large health networks was to "increase the efficiency and effectiveness of medical services for people who use services , particularly those at risk of poor health outcomes, and improve coordination of care to ensure they receive the right care in the right place at the right time". The aim of establishing PHNs was to reduce fragmentation of care by integrating and coordinating health services, along with supporting the role of general practice, and leveraging and administering health program funding.<sup>(21)</sup>

PHNs are closely aligned with the state and territory Local Hospital Networks (LHNs), they work directly with general practitioners, other primary healthcare providers,



secondary care providers and hospitals to facilitate improved access to primary care services, better coordination with local services, and enhanced access to frontline health services in their local area and ultimately improved outcomes for service users. The focus of establishing PHN networks was to integrate public healthcare into the primary health care landscape, providing capacity to ensure that health services were more accessible and tailored to community needs, while producing cost savings through reducing preventable hospitalisations and improving care coordination, predominantly for those at risk of poor health outcomes.

PHNs manage all aspects of primary healthcare in their region including mental health. They have been tasked by the Australian Government with addressing six key priority areas to include, Aboriginal health, aged care, e-health, population health, mental health and health workforce.<sup>(21)</sup>

PHNs are assigned with identifying and resolving service provision gaps in a costeffective manner. In many cases, these gaps, once revealed, are filled by negotiation with existing providers. However, PHNs have access to flexible, discretionary, Commonwealth provided funding to commission external healthcare providers to meet the gaps in requirements identified in their region.

PHNs manage their region by tailoring health services to the needs of the community and adapt their approach to connecting services, therefore each region applies a different model but all are guided by the national priorities set out by the Australian Government.

Since 2016, the Australian Government Department of Health and Aged Care has funded primary health networks (PHNs) to implement primary mental healthcare reform.<sup>(23)</sup>

#### Establishment of Head to Health services for mental healthcare

Head to Health (H2H),<sup>(24)</sup> is a service provided by the Australian Government's Department of Health and Aged Care. It was established following the 2020 -2021 Productivity Commission<sup>6</sup> Inquiry Report on Mental Health. The inquiry report highlighted the complexity of the mental health system and how many people who needed treatment and care were unable to access appropriate services. It also noted the impact of COVID-19 on the wellbeing of the mental health community with regard to needs and services.

Following the Productivity Commission Inquiry Report, the Australian Government invested in the establishment of Head to Health (H2H) Centres and satellite

<sup>&</sup>lt;sup>6</sup> The Productivity Commission (PC) is the principal review and advisory body for the Australian Government released its Inquiry Report on Mental Health in Australia.



networks of community-based adult mental health services to be delivered by multidisciplinary teams, providing holistic, collaborative care embedded into existing primary care settings. Funding was also provided for a central intake and assessment telephone service that promotes consistent triage and enables transfer and referral to the most appropriate services.

H2H is a National Digital Mental Health Gateway, which aims to help people access the mental health and wellbeing services that are right for them. It comprises the Head to Health digital platform, the Head to Health Phone Service and a network of Head to Health centres. The services make it easy for individuals to navigate and allow them to choose the most suitable care options for themselves, whether that is face-to-face, via telephone or online.

Head to Health also makes it easier for GPs and other health professionals to support the mental health of the people they look after, and those who support them, through improving access to, and coordination of, mental health services in their local community.

Head to Health services provides a suite of entry points into mental health services offering options for engagement, assessment and treatment for people with mental health needs. Entry points comprise its digital mental health platform which includes a comprehensive national mental health website, containing up-to-date information, tools, and resources to support people's mental health journey, a free confidential national Head to Health phone service which acts as a central point for people to speak to someone about mental health issues along with Head to Health centres and Pop Up clinics and a Head to Health Kids Hub. These entry or contact points aim to support and connect people to appropriate mental health care in the community, close to where they live.

Head to Health services are intended to complement, not replace or duplicate mental health services already provided in the community. They are not designed to offer longer term ongoing care but are based on an episode of care model, delivering packages of evidence-based care and family support to cover the short to medium term, based on clinical judgment and individual need.

People may self-refer to Head to Health services using their preferred platform (website, phone, face to face) or GPs, psychiatrist, and other health professionals may refer to find service options for people who use services.

Head to Health services are targeted at supporting adults 18 years and over. Anyone living in Australia can call the free phone number to be connected to an experienced mental health clinician who can assess their needs and help them get the right advice and support in their local area.



#### The relationship between NWMPHN and Head to Health services

All PHNs in their role as service managers have responsibility and accountability for the implementation and financial oversight of the Head to Health commissioned services in their region. However, the Australian Government appointed North Western Melbourne PHN to provide support for the national Head to Health programme. NWMPHN provides support through:

- A national shared telephony infrastructure: North Western Melbourne PHN (NWMPHN) is responsible for the infrastructure, administration and management of the national telephony<sup>7</sup> phone line across all PHN regions. All H2H phone calls are routed from the national central line based on the clients' postcode to local intake teams servicing each PHN region. Once calls have been routed from the central line, the call becomes the responsibility of the receiving intake team i.e. the local Head to Health service.
- A workflow management and data collection application: The use of various application programming interfaces (APIs) to enable secure connections to authorised software, facilitating communication through multiple platforms, the sharing of data and the elimination of duplication when using Head to Health or other service providers. The implementation of a shared national telephone infrastructure, along with the requirement of H2H services to apply a standardised approach when assigning a recommended level of care and informing a referral decision using the Initial Assessment and Referral Decision Support Tool (IAR-DST)<sup>(25)</sup> allows insights into local and national services and trends.
- A consumer experience platform: The Head to Health Data Management System includes a consumer experience survey. This means that every person who contacts the Head to Health phone service or visits a Health to Health centre can provide anonymous feedback on the service and support they receive, through both the Head to Health (H2H) Initial Intake Experience Survey and the Head to Health (H2H) YES PHN Survey.
   NWMPHN partnered with Cemplicity (a specialised patient reporting software company working with providers in healthcare settings) to deliver and manage the survey, capture feedback and provide PHNs with access to a comprehensive and secure reporting portal that enables survey responses to be viewed and analysed in real time.
- A national analytical and reporting infrastructure: A shared infrastructure enables integration and linkage of key datasets and upload of

<sup>&</sup>lt;sup>7</sup> Telephony refers to the use of telephonic equipment to communicate, to include voice communication, text messaging, video calling, video conferencing, voicemail, call recording and faxing.



data to the Australian Government's Primary Mental Health Care Minimum Data Set (PMHC MDS)<sup>(26)</sup> portal. This allows for data to be measured at local and national level for service evaluation and improvement.

All PHNs are required to report on all contact activity data to the Department of Health each month to provide a greater understanding of mental health needs across Australia. The data collected consist of phone call activity including the number of callers, the Initial Assessment Referral level of care, referrals to PHN commissioned services, referral out destination, and demographic characteristics of consumers. Data is reported by PHNs to the Primary Mental Health Care Minimum Data Set (PMHC-MDS). To complement the data, service user experiences of care surveys are also carried out.

Evaluation of the services provided by Head to Health (in community settings) take place in two phases:

- 1. Head to Health (H2H) Initial Intake Experience Survey
- 2. Head to Health (H2H) Your Experience of Services (YES) Primary Health Networks Survey

NWMPHN networks have responsibility for managing the administration of the Head to Health (H2H) Initial Intake Experience Survey and the Head to Health (H2H) YES PHN Survey, using a third party to gather and collate the survey data, that is to say, Cemplicity. This allows NWMPHN to monitor the performance of H2H providers and evaluate consumers' experiences of services.

Name	Target	Delivery	Areas covered
Head to Health	All consenting	Day after intake	This survey is used
(H2H) Initial	H2H consumers		nationally, NWMPHNs
Intake Experience	after intake		role is to manage
Survey			(through Cemplicity)
			the administration of
			the survey for the
			other participating
			PHNs (approx. 26
			nationally)
Head to Health	All consenting	After 3-months of	This survey is run
(H2H) YES PHN	H2H consumers	treatment or	specifically for
Survey	after treatment at	closure of	Victorian PHNs for
	H2H centres	treatment	Head to Health
			services only. The

#### **Table 1: Head to Health Surveys**



(whichever is	NWMPHN use a
first)	managed service
	(Cemplicity) to collect
	and report the data
	for Victorian PHNs

#### Head to Health Referral and Assessment Initial Experience Survey

The Head to Health Referral and Assessment Initial Experience Survey is offered to every person who contacts the Head to Health phone service, or who walks into a Head to Health service/hub. This is the point where a person has their first assessment and referral to further treatment or services (if required).

Following consent (be it signed in person or agreed and documented from a telephone consult) at the point of referral, consumers are automatically sent an invitation link to complete the Head to Health Initial Experience survey 24 hours after their initial contact, (the Head to Health survey is not shared if a person is admitted or referred to an emergency/crisis service). The person's telephone number (for SMS) or email is recorded in order to share the survey link with them.

The survey focuses specifically on the referral and assessment experience only and is made up of 13 questions, broken into four sections. The sections include questions on:

- why the consumer contacted Head to Health
- what their intake experience was like
- a free text box to describe how their experience could have been better and
- a section on consumer demographics.

The purpose of the initial experience survey is to learn from consumer experiences to improve the Head to Health 'assessment and referral' services.

A comprehensive and secure reporting portal/dashboard is provided by Cemplicity,<sup>8</sup> the survey administrators and it is made available to PHNs and service providers to enable survey responses that can be viewed and analysed in real time. In addition to having access to the secure portal, PHNs and service providers receive regular reports. The reports include findings on consent rates, experience scores, free-text comment 'quotes' and demographics.

As of 2023, Head to Health hubs and phone support have helped more than 10,000 people in the NWMPHN region access mental health support.

<sup>&</sup>lt;sup>8</sup> A specialised patient reporting software company working in healthcare settings with providers.





The NWMPHN (H2H) Initial Intake Experience Survey findings since its commencement in July 2022 to August 2023 demonstrated a 22% response rate. With medical professionals and GPs identified as the main source of hearing about the services. Over 60% of respondents self-identified as female.

#### YES PHN survey/ (Head to Health commissioned service)

NWMPHN administers the YES PHN survey through its commissioned primary mental health care providers. PHNs use the Your Experience of Services Primary Health Networks (YES PHN) survey which is a variant of the YES survey.<sup>(27)</sup>

The YES PHN survey questionnaire<sup>(15)</sup> was developed in consultation with mental health consumers. It is based on the recovery principles of the 2010 National Standards for Mental Health Services. The project to develop the YES PHN survey was funded by the Australian Government Department of Health, and was led by the Australian Mental Health Outcomes and Classification Network (AMHOCN).<sup>(28)</sup>

The YES PHN survey is designed to gather information from mental health consumers about their experiences of care with services commissioned by PHNs. Its aim is to help PHNs, their commissioned service and consumers to work together to build better services.

It is a nationally validated Participant Reported Experience Measure (PREM) and is used to benchmark good practice and compare outcomes of services and care.

PHNs must engage in a licensing agreement to obtain and use the YES PHN survey.<sup>(29)</sup> The arrangement is in place to promote the consistent use of the survey tool, to discourage unnecessary modifications and to prevent the use of the survey instrument for profit.

The North Western Melbourne YES PHN survey is used to evaluate the Head to Health (H2H) commissioned services in the region.

NWMPHN has partnered with a third party, specialised patient reporting Software Company working in healthcare settings called Cemplicity. The third party, administer, collate and report the YES PHN Survey data and findings.

Consumer data is reported and uploaded by PHNs and service providers through a secure password protected file to the Primary Mental Health Care Minimum Data Set (PMHC-MDS).<sup>(30)</sup> Data included in the PMHC-MDS is used to send invitations to consumers who have completed an episode of care at Head to Health (H2H) centres within a specific time period to complete a YES PHN survey. The H2H commissioned and funded providers send the survey out on behalf of the NWMPHN for the YES PHN survey as only they have their contact details.



Consumer data to include name, mobile number and email is uploaded monthly using a secure file extraction, to allow the survey link or QR code to be sent to the consumer to complete the YES PHN survey.

The H2H service providers have the option to personally brand and design their own YES PHN survey invitation to invite consumers to share their experiences.

By helping to identify specific areas where quality improvements can be made, the YES PHN survey supports collaboration between mental health services and consumers to build better services.

The YES PHN survey is then carried out with people who are referred for H2H community treatment or care in H2H centres.

The YES PHN survey asks people who use commissioned mental health services about their experiences of care received in a community service in the previous three months or less. Consent to participate is taken at the time of referral. A link is provided by SMS, or email to complete the survey or a QR code is also available.

PHNs assign providers with a unique code for service provider identification purposes, categorising the service type and organisation.

The YES PHN data is managed by the PHNs and the consumer details is uploaded by the provider organisation to the PMHC MDS system.

#### 3.2 Governance

Primary Health Networks (PHNs) are responsible for managing all primary health care in their region including mental health. All PHNs are required to report on all mental health contact activity (telephone and in person activity) data to the Department of Health each month and to carry out surveys on consumers experience of care to provide a greater understanding of mental health needs across Australia.

#### **3.3 Commitment**

In Australia, the National Safety and Quality Health Service Standards stipulate that health services have processes in place to seek regular feedback from people who use services, carers and families about their experience of care. The YES PHN survey is based on national standards of service delivery and the principles of recovery.

#### 3.4 Data protection

All information collected in the YES PHN survey is confidential and anonymous. None of the information collected is used to identify participants. The YES PHN survey does not record the name, date of birth or any personal identifiers of consumers.



Completion of the YES PHN survey is voluntary, there is no pressure to participate. By completing the survey, the consumer is implicitly giving their consent for the information they provide to be used by the H2H and PHN organisation.

#### **3.5 Ethical approval**

Under the National Health and Medical Research Council NHMRC guidelines on ethical conduct in human research<sup>(31)</sup>, ethics is not required where health service organisations use the survey for quality improvement purposes. However, organisations are advised when using the YES PHN survey they should review the purposes that are being pursued to ensure they comply with the NHMRC guidelines and their own local policies.

#### 3.6 The survey

The YES PHN survey asks consumers about their experience with the PHN service in the previous three months or less. The survey is offered in the English language only, it comprises of a total of 26 questions, and takes 8-10 minutes to complete.

The survey uses two five point Likert-style rating scales to record the responses to the individual items.

Sixteen questions relate to experience of care, question 1-9 (9 questions) ask about the care provided with a **frequency scale** rating of never, rarely, sometimes, usually to always, with a not applicable option provided.

Questions 10-16 (7 questions) ask about how well the service provided did, with a **performance scale** of poor, fair, good, very good, excellent or not applicable. There were two free-text open-ended questions asking what 'was good' about the service or 'what could have been better' and the remaining 8 questions covered demographics.

#### 3.7 The sample

The NWM YES PHN survey is implemented routinely on an ongoing basis. All consented consumers (consented by sharing their contact details to receive the survey link by SMS or email) in H2H community settings who have received care/services are offered the survey three months after care or at discharge whichever comes first. Consumers experiencing an acute episode are not included in the survey population due to their critical mental health needs at the time.

#### 3.8 Distribution and collection

The PHN YES survey is offered to consented consumers after they have received three months of care in a community setting or at discharge, whichever comes first.

PHNs assign providers with a unique code for service provider identification purposes, categorising the service type and organisation.



There is a key number or code assigned to each individual client referred to the commissioned organisation. The client identifier is unique and stable for each individual within the provider organisation.

The YES PHN data is managed by the PHNs and the consumer details are uploaded by the provider organisation to the PMHC MDS system through a secure CSV file.

NWMPHN's contractor Cemplicity administers, collates and reports the YES PHN Survey data and findings.

Access to the person's telephone number (for SMS) or email is required in order to share a link with them to invite them to complete the survey.

Invitations are valid for seven days

- Two days after the invitation is sent, a reminder to complete the survey is sent and also reminding consumers of the date on which it will expire.
- Six days after the invitation, reminder sent to complete the survey and reminding them it will expire the next day.

After the invitation is sent the mobile number and or email address is discarded.

The NWM YES PHN survey is presented in a visual mode, so that consumers can see all options at once and record their responses, this is achieved by paper-based forms or electronically via on screen formats, or by SMS on mobile devices or by accessing a survey QR code.

#### **3.9 Communication and Publicity**

In the case of the NWMPHN consumers are informed of the YES PHN survey by their referring GP or by the clinical teams at the point of initial assessment and referral. The reviewing clinical team seeks the agreement of the person using the services to share their contact details such as telephone number (SMS) or email address in order to receive the survey link to participate in the surveys.

The opening section of the YES PHN survey, provides an explanation of the purpose and aim of the survey for participant consumers, which also addresses confidentiality, the voluntary nature of participation and where to obtain any additional information, if required.

A participant information sheet is also available on request prior to participating in the survey.

To enhance consumer participation and for display purposes, survey resources and educational material such as posters and video links are provided by NWMPHN to all its regional H2H community mental health service providers.

Survey QR codes are also displayed and shared with consumers



Training and education to support the consumer consent process and participation in the survey is provided to service providers.

#### 3.10 Response Rate

PHNs use the aggregated results for quality improvements, and a 50% response rate (of those offered the survey) is considered desirable.

It is also important to ensure the sample is representative of the population of consumers attending the commissioned provider H2H services.

#### 3.11 Analytical methodologies

The YES PHN survey is offered in the English language only, it is made up of a total of 26 questions, and takes 8-10 minutes to complete.

The survey uses two five point Likert-style rating scales to record the responses to the individual items.

Sixteen questions relate to experience of care, questions 1-9 (nine questions) ask about the care provided with a frequency scale rating of never, rarely, sometimes, and usually to always, with a not applicable option provided.

Questions 10-16 (seven questions) ask about how well the service provided did, with a performance scale of poor, fair, good, very good, excellent or not applicable. There were two free-text open-ended questions asking what 'was good' about the service or 'what could have been better' and the remaining eight questions covered demographics.

Numeric value to be assigned					
Scale	1	2	3	4	5
Frequency scale	Never	Rarely	Some-times	Usually	Always
Performance scale	Poor	Fair	Good	Very Good	Excellent

Numeric values are assigned to the consumer responses:

To support consumer understanding of reports and to make more meaningful reporting for quality improvement purposes **six key domains** for reporting the results were identified:

- Making a difference: This domain looks at how services contribute to individuals' outcome including social and emotional wellbeing and physical health. (Q13, Q14, Q15, Q16)
- Providing information and support: This domain seeks to explore how the service works for the individual – providing resources such as written information, a care plan, access to peer support. (Q10, Q11, Q12)



- Valuing individuality: This domain seeks to identify if services meets individual needs, is it sensitive to culture, gender, faith and the importance of personal values and beliefs. (Q5, Q6, Q9)
- Supporting active participation: This domain explores how services provide opportunities for engagement, choice and involvement in the process of service delivery. (Q3, Q4)
- Showing respect: This domain looks at how services provide individuals with a welcoming environment, where they are recognised, valued and treated with dignity. (Q1, Q8)
- > **Ensuring safety and fairness:** This domain looks at how services provide individuals with a physically and emotionally safe environment. (Q2, Q7)

A third party specialised patient reporting software company administer, collate and report the YES PHN Survey data and findings.

#### 3.12 Output

The YES PHN Survey findings are presented in a dashboard by the survey administrators which gives PHN networks and providers access to real time survey results that can be accessed at any time by nominated representatives of the organisation. The third party survey administrators provide training and access to the dashboard to nominated representatives of providers.

Quarterly and annual reports are provided at local, regional and national level to inform and support the Australian government's future improvements in the planning and funding of primary mental healthcare services.

#### 3.13 Impact

The YES PHN survey carried out in NWM allows NWMPHN to monitor the performance of H2H commissioned providers and evaluate consumers' experiences.

The YES PHN survey is a nationally validated participant reported experience measure (PREM) and is used to benchmark good practice and compare outcomes of services and care.

Commissioned services across Australia use the same survey, which allows consumer feedback to be combined and reported on at a local and national level, identifying areas that work well and areas that can be improved.

The dashboard provided by the survey administrators contains a range of numeric data and thematic analysis of consumer feedback that is used by PHNs and commissioned services to support continuous quality improvement.

Findings demonstrate client satisfaction with programmes and services and support further grant or funding applications by PHN networks.

The data reported through the PMHC-MDS along with the survey findings forms the basis for the production of key performance indicators used to monitor services



delivered across the 31 PHN regions and allows comparison and insights into different commissioned services.

#### 3.14 Key recommendations and lessons learned

- 1. The clinical team at the point of assessment/referral introduce the surveys which enhances its validity, taking contact details at this point also streamlines the process for survey engagement. (H2H Initial Assessment and Referral Survey).
- 2. SMS and email contact are used to send the survey links.
- 3. The survey is short with 26 questions and only takes 8-10 minutes to complete.
- 4. NWMPHN has partnered with a third party, a specialised patient reporting software company working in healthcare settings. The third party administers, collates and reports the YES PHN Survey data and findings.
- 5. By undertaking and reporting on the survey monthly, NWMPHN and commissioned services in primary mental health care can measure and monitor changes in consumers experience over time and assess whether actions and changes implemented are improving the quality of their experiences.
- 6. Conducting surveys remotely using SMS or email with the need for access to Internet/Wi-Fi can be a limitation for socially remote, low socio-economic or minority groups.
- 7. When using SMS or emails as a survey model consideration needs to be given to the fact that individual consumers may complete a survey more than once in a reporting period.
- 8. Of note, the YES PHN survey is offered in the English language only.



## 4. Denmark

#### **Denmark – International Review**

The information outlined in this review was obtained from conversations with the team in Defactum.<sup>9</sup>

#### 4.1 Overview/Background

Denmark is located in northern Europe, and consists of the northern part of the Jutland peninsula. It occupies a total area in excess of 42,000 square kilometres and 406 islands. As of February 2024, Denmark has a population of 5.9 million<sup>10</sup> people.

The Danish healthcare system is a public, mainly tax-funded healthcare system with free access to hospital care for all Danish residents. It is run and organised across three administrative systems, the state the regions and the municipalities. The five regions in Denmark, (1.Capital Region of Denmark, 2.Region Zealand, 3.Region of Southern Denmark, 4.Central Denmark Region, and 5.North Denmark Region) are responsible for hospitals (somatic<sup>11</sup> and psychiatric), and local community mental health centres, self-employed healthcare professionals such as general practitioners, specialists, and dentists and so on. In the case of mental health, if hospitalisation is required, people with a psychiatric disorder have free access to psychiatric hospital care. However, mental healthcare is mainly provided in primary care or outpatient settings.

In Denmark, entire Danish population information on health, social and economic issues are collected, stored and managed in national registers. The Danish Health Data Authority has responsibility for the health registers, there are in excess of 70 health registries which capture many different types of data to include: The National Birth Register, The National Cancer Register, The Cause of Death Register, The Danish Pathology Register, The Psychiatric Treatment Register and the largest data source which is The National Patient Register (NPR).<sup>(32)</sup>

However, the social registers are solely held by Statistics Denmark. Statistics Denmark is responsible for all social data information and registers such as national statistics for education, employment, income, building and housing and so on.

<sup>&</sup>lt;sup>9</sup> DEFACTUM is a research and consultancy firm that collaborates with private and public clients and partners at regional, national and international level, to transform the latest knowledge about public health into specific and targeted efforts and improvement projects. The purpose of DEFACTUM is to create collaboration between practice, research, and the political-administrative levels within healthcare, social services, and the labour market.

<sup>&</sup>lt;sup>10</sup> Statistics Denmark is a Danish governmental organisation responsible for generating statistics on Danish society, for example employment statistics, trade and demographics and so on. http://www.dst.dk

<sup>&</sup>lt;sup>11</sup> The term Somatic refers to physical or medical to include hospitals, care or conditions.



Further examples of health and social databases can be found at <u>www.kliniskedatabaser.dk</u>.

Danish national data on the total population has been collected since the 1970's, over 40 years. It is unique because it covers all areas of the health and social sector, and it includes data on the entire Danish population from birth to death. The extensive, consistent collection of this data over a long period of time contributes to its quality and validity ensuring it is of a very high standard.

All permanent residents of Denmark are allocated a unique personal identification number, called a civil registration number (CPR) the number which is assigned at birth or by becoming a citizen of Denmark, is recorded in the Civil Registration System. The CPR number makes it possible to link data across the national registers in Denmark. This provides a rich repository of knowledge and insights on national population health.

In Denmark, health data is collected every time a person visits their GP, the hospital or a medical specialist, buy medicine at the pharmacy or receive health services in the community. Data is entered into the National Patient Register via the local electronic health record system or through the Danish Health Data Authority's Electronic Registration System. This data is collected in the national health registers.

In Denmark, authorities use digital post to communicate with Danish citizens it is a secure way of sending and receiving personal, sensitive and general data protection information. All legal residents over the age of 15 years in Denmark, receive their post from public authorities digitally. Individuals have a single mailbox for all mail and communication. The 'Digital Post' refers to both the mailbox and the messages and ensure secure digital communication between citizens and the public authorities. Digital post is synchronised across all platforms.

#### 4.2 Governance

The Danish National Survey of Patient Experiences was established in collaboration between the Ministry of Health and the Danish Regions.

LUP (Landsdækkende Undersøgelse af Patientoplevelser), "Nationwide Survey of Patient Experiences" is implemented by DEFACTUM<sup>(33)</sup> on behalf of the five regions.

The Danish National Surveys of Patient Experiences was established in collaboration, between the Ministry of Health and the Danish Regions and are carried out annually.

Feedback from people who use services and relatives in LUP Psychiatry provides a picture of their experiences of their care and their contact with the care provider, unit or hospital.

This feedback allows individual units to identify areas where quality improvements and change are needed, identify and compare differences inpatient experiences



within selected themes, follow the development of the person using services experiences over time and allow decision makers to compare territories and regions.

#### 4.3 Objective

LUP Psychiatry is the national survey questionnaire that explores how people who use services and relatives experience their encounters with public hospital psychiatric services. The survey has been carried out in mental health since 2005. The survey provides the country's regions, hospitals and departments with feedback and insight into the experiences of people using services. It consists of nine surveys with questionnaires and survey concepts adapted to the individual specific needs of each of the target groups. It is divided into five patient groups and four groups of relatives.

	Patient Groups (5)	Relative Groups (4)
1.	Adults (hospitalised/in-patient)	Relatives of hospitalised adults are only surveyed every 3yrs
2.	Adults (ambulatory/out-patient)	Relatives/nominated person of out- patient adults are only surveyed every 3yrs
3.	Children and Youths If under 11yrs	If a child is under 11yrs, parents are asked to complete survey <b>along with</b> input from child (where appropriate)
4.	Children and Youths If 12-18yrs Child or youth completes	Parents of children and youths 12- 18yrs are asked to complete a separate survey of their own
5.	Specialised Forensic Psychiatry inpatients – get a shorter questionnaire	

#### 4.4 Commitment

Danish national healthcare policy and legislation demonstrates commitment to improving the quality of care received by people who use services by measuring and reporting the experiences of people who use services to further develop and enhance healthcare services for service users. People who use services and relatives are recognised as important partners in creating change.

#### 4.5 Data protection

The Danish Health Data Authority is an agency under the Danish Ministry of the Interior and Health. The Authority has responsibility for the collection, storage and management of Danish health data in national health registers. Data is processed based on legal requirements and therefore consent is not required in the processing of health data.



The Danish Health Data Authority is responsible adherence to General Data Protection Regulation (GDPR) with strong cyber and information security in place.

In the case of the original psychiatric paper survey, all survey participants were identified at local service level by staff working in the area, the anonymised survey responses were posted back in prepaid envelopes or collected in sealed envelopes and returned to the research team at Defactum for analysis and interpretation. Data sharing agreements were in place with each of the five regions to identify and access eligible patient and relatives' datasets. Completion of the survey implies participants have given consent.

Since the introduction of the monthly digital survey model in 2022, participants are identified through the psychiatric registers (information of people who use services/encounters is completed by the hospital/service into the registers) and invited to complete the surveys through their individual's digital mail box and responses are anonymised and directly processed by the Defactum research team. The new model is identified as a research project, which gives access to the registers datasets and therefore data sharing agreements are not required.

#### 4.6 Ethics

Ethical approval is not required for experience surveys for those who use services as the surveys are carried out in the public interest. The Danish regulations on HealthCare data ensures that data can only be used provided it meets the basic requirement of general societal importance.

#### 4.7 The survey

In the case of adult psychiatry (unit/hospital or ambulatory/outpatient setting), the original, annual paper format survey of both the inpatient and outpatient groups was carried out for the first time in 2005.

To streamline the process of delivering questionnaires and to make it as easy as possible, all survey materials are packaged in sets by Defactum. A questionnaire set/pack consists of:

- Cover letter (in some cases printed on the front of the questionnaire)
- Questionnaire
- Registration sheets
- Reply envelope.

Cover letters are designed specifically for specified units or wards and signed by the nominated person in that area.

The cover letter, questionnaire and registration sheet contain the same unique serial number that is used to link the registration sheet to the questionnaire. Only the specific registration sheet included in the questionnaire pack can be used when



handing out the questionnaire to an individual who uses a service. For this reason if the questionnaire is discarded, the cover letter and registration sheet specific to that pack must also be discarded.

To allow for electronic completion of the survey both the cover letter and the questionnaire include a web address and a login password so that people who use services (and relatives where relevant) who wish to complete the questionnaire online can do so.

The survey consisted of between 25 and 35 questions. Nine national questions across all regions were asked for all people who use services and family groups to include: reception/visit or admission, staff, treatment, and relative involvement, coercion during hospitalisation, coherence and collaboration, discharge and overall impression.

Each region/hospital and department had the opportunity to choose a number of local questions themselves, to measure the part of the patient experience that they would like to improve locally. The choice of local questions to be included are provided from a catalogue of tested and approved additional questions.

In 2022 with the advancement in eHealth and digital technologies, the survey was changed to a digital model and was commenced for people who use adult inpatient and outpatient mental health services (not forensic mental health) through their digital mailbox, subsequently the digital survey model continues to take place monthly.

#### 4.8 Sample

Prior to 2022, in the case of the annual adult inpatient survey, patients admitted to adult wards during the study period and who were about to be discharged or transferred were eligible to participate.

While the eligibility for the ambulatory/outpatient survey group required eligible people to have had personal contact during the study period with one or more therapists in outpatient adult psychiatry services, and must have had at least three personal contacts in the current treatment period.

As regards the relative adult survey, in either the inpatient or outpatient group, relatives of people who use services in the target group are eligible to participate however, the patient/person using the service decides which relative/caregiver they wish to participate. The 'relative/caregiver' could be a family member, a colleague, friend, a neighbour or other, it **could not** be a member of staff in the service area.

Relatives are only surveyed at three-yearly intervals. On the year when relatives were also surveyed a unique assigned identifier on the two distinct questionnaires for the person and their caregiver allowed their data to be linked indirectly.



#### 4.9 Distribution and collection

The surveys were conducted according to a fixed schedule each year, with the distribution and collection of questionnaires in the autumn and reporting in the spring, over a four-to-six week period for inpatient users and outpatient users respectively.

In each of the five regions, a coordinator was appointed with responsibility for the regional organisation and implementation of the survey.

Local coordinators (survey managers) were appointed in hospital/outpatient settings to support the survey implementation process.

Defactum handled the printing, and packaging of all survey materials and associated materials and they provide these to local coordinators in service areas via the regional coordinators. Support is also provided through information training and contact details during planning and implementation of the survey model.

From the commencement of the adult psychiatric service user experience surveys in 2005, staff working in the service area identified the eligible participants to take part in the survey prior to their discharge from services. The research team did not have the names and contact details of the person invited to take part in the survey therefore no survey reminders could be sent to survey participants.

In the case of adult psychiatric inpatient users it is recommended that the survey questionnaire is given to the patient as close to discharge/transfer as possible, but it should be at a time when the patient has peace and quiet to complete it, preferably two-to-three days before discharge/transfer.

Each outpatient clinic and section had a local coordinator responsible for the practical implementation of the survey. The local coordinators and staff personally handed out the survey questionnaires to eligible participants in accordance with the criteria set.

The person handing out the questionnaire must take the registration sheet out of the pack and complete it, the individual can be the one to provide these details or give consent for staff to find the information in the person's medical record. The registration sheet requires the following details:

- The person using the service's CPR number
- Length of service user contact with the service
- The person using the service's diagnosis and legal status (for adults)
- Package pathway (outpatient users).

It is the responsibility of the local coordinator to ensure that all registration sheets are collected and sent to DEFACTUM once a week during the study period in the large response envelopes that are provided and stamped.



In the years (three yearly) when the next-of-kin/relatives/caregivers were surveyed in adult psychiatry, (based on the individual's consent and information supplied) the address of the person who was to be sent a questionnaire was also required and included in the registration sheet.

Prepaid envelops were provided, and a simple style post box was also created to support the return of surveys if completed in hospital or on a return visit. The local coordinator had responsibility for emptying the post box and returning the completed surveys to Defactum.

Questionnaires could also be returned to the research team in Defactum directly by the survey participant using the prepaid envelop provided.

Survey questionnaires also have a link and password to allow participants to complete the survey online. It is the responsibility of the local coordinator to provide internet access so that inpatient users (and relatives when applicable) can answer the questionnaire electronically if required.

People were able to withdraw at any point from completing the survey questionnaire, however, once the survey was submitted the person could no longer withdraw as all survey responses were anonymised.

Participants could complete the survey with the support of a relative but staff members in the service area could not complete the survey on behalf of an individual.

Scanning of completed survey questionnaires and data processing handling was carried out by the research team at Defactum.

#### 4.10 Communication/Publicity

To create awareness of the survey, hospital/unit staff and outpatient departments were provided with promotional material and resources such as animations, posters, postcards along with a video film for information screens and websites to inform and motivate people who use services and relatives to participate in the survey.

It is the responsibility of local coordinators to ensure that all people who will participate in the distribution of the survey questionnaires are informed about the survey and their role in it. To support staff in their role, a brief information leaflet was provided for them. It is also recommended that staff are made aware of the survey at staff meetings, or in whatever way it is deemed most appropriate at local level. A PowerPoint presentation is provided as an aid/supplement for promotion of the survey.



Employees who hand out the questionnaire were encouraged to inform people who use services about the survey and to explain its purpose such as the survey contributes to good services for psychiatric patients in Denmark.

The surveys are anonymous, and the results are presented in such a way that no individual response can be recognised.

#### 4.11 Response rate

From its commencement in 2005 until 2022, staff on hospital wards or in out-patient settings were responsible for handing out the survey questionnaire to eligible participants, during this time there has been a minimum 50% response rate.<sup>(34)</sup>

## The 2021 National LUP Psychiatry survey respondents were broken down into inpatient and outpatient adults groups

	Number of responses	Response rate
Hospitalised patient	1802	66%
Ambulatory/Outpatient	4954	61%

Respondents answered on a 5-point scale ranging from 1 (not at all) to 5 (very much). For data analysis, responses were grouped into the following categories 3 and below, 3.01 -3.50, 3.51-4.00, 4.00 and above.

#### Hospitalised Question Ambulatory adults adults patients patient 1 All in all, I am satisfied with my visit/admission 4.35 → 4.06 → 2 A certain doctor takes overall responsibility for 3.95\* 3.71\* my overall course The staff is friendly and accommodating 4.39 → 3 4.67 → I can get in touch with the staff if necessary 4.28 → 4.17 ↑ 4 5 The staff asks about my description of the 4.30 → 3.85 → illness/condition I help make decisions about 4.22 → $3.73 \rightarrow$ 6 examination/treatment 7 I get the information I need 4.27 → **3.87** → I get help to deal with psychological difficulties 3.79 → 4.22 → 8 9 The staff talk to me about what I can do to get 4.17 → $3.64 \rightarrow$ better

#### Table 2: Data analyses of high and low scoring questions

(Relatives are only surveyed every three years – most recently carried out in 2021)



#### 4.12 Analytical methodologies

Data analysis was carried out by the research team at Defactum.

The survey questionnaire primarily used ordinal questions (Likert scale agreement) with some closed-ended questions which were categorical/nominal (yes/no/don't know), continuous (age) and the questionnaire also has between two to four open text comment fields (qualitative variables). There are up to five annual theme questions for each patient and relative group.

Data analyses was carried out using a 5 point scale of agreement, from 1 (not at all) to 5 (very much), with options of `not relevant to me' or `don't know' and questions with Yes/No answer options. Yes could be a negative or a positive answer, depending on the wording of the question the person was asked.

Demographic data is also collected from the survey participant and can be broken down according to age, gender, diagnosis groups, duration of contact (outpatient user), duration of hospitalisation (inpatient user) and regions.

The information on the registration sheet which is included in each survey pack is used:

- To calculate survey response rates
- To analyse the impact of background information on satisfaction
- To compare background information on respondents and non-respondents

Reporting of results from the person using the service and parent/careers groups take place approximately six weeks after data collection has ended.

#### 4.13 Outputs/Results (Local and regional):

The results for LUP Psychiatry are reported nationally and at regional, departmental/hospital and unit level.

Results are available to the public on the official portal for the Danish healthcare services.

At unit level the results are used to identify areas for improvement, benchmarking and monitoring of development over time.

Results are only reported at unit and department level when at least 10 questionnaires have been handed out and at least five responses have been returned. To ensure anonymity and confidentiality. Results from sections with fewer responses are included in the overall results at higher organisational levels.

The departments have access to preliminary data via electronic access, where the results contain the answers from both the scanned paper forms and online responses approximately two weeks after data collection has ended.

The municipalities and regions use the data from the health surveys to formulate health policies and to plan specific health initiatives.



Following analyses, the responses of the survey findings are shared with the units/wards/hospitals involved, the results are assessed, areas of improvement are identified and a plan of action is prepared by the unit/ward/hospital and improvement initiatives are implemented.

The survey tool identifies and supports quality improvements nationally and locally in the regions. LUP also making it possible for regions, departments and units to compare their own results for LUP Psychiatry with previous year's results and thus monitor development and change over time.

#### 4.14 Lessons learned

- Implementation of a paper survey model prior to discharge from services requires more resources, time and personnel to administer the process, consequently, this creates a greater workload and burden on staff.
- As the local coordinators and staff identified the survey participants this may lead to survey bias and/or may impact participant responses.
- The research team recommended keeping the survey questionnaire short, as they had received positive feedback when they had shortened their survey questionnaire.
- The research team also suggested not leaving too long between discharge and sending out the survey to this population, as they found that participants' memory recall is better closer to their discharge timeframe rather than later and they are more motivated to complete the survey at this earlier stage.
- Response rates for people using outpatient services is greater than those receiving inpatient care; however, this is to be expected as there is a larger concentration of people using outpatient mental healthcare services and people who use inpatient services may not be as well or engaged as those in outpatient settings.

The new digital survey model commenced in 2022 by Defactum.

From 2022, LUP switched to monthly measurements for adults receiving psychiatric care, in both inpatient and outpatient settings (except for those admitted to the specialist forensic psychiatry).

In October 2022 for the first time, the survey was carried out digitally to both adult inpatient and outpatient groups.

Every month, the sample is randomly generated on the basis of an extract from the National Patient Register. Datasets captured from the Danish National Patient Registry are used to contact relevant survey participant through their digital mailbox to complete the specific survey.

The Danish Health Data Authority sends out the questionnaire to random people who use services in the target group. Questionnaires are sent out (by digital post) to



the sample of adults who use services for all departments that fall within the LUP Psychiatry's inclusion criteria.

An individual has a month to respond to the survey questionnaire. For example, a patient who is discharged in April receives a digital form at the beginning of May – and has until the end of May to respond. The individual receive two reminders during May if they have not responded.

Once a participant presses "finish" at the end of the survey questionnaire link, the form cannot be opened again and therefore the answers cannot be changed.

In the case of the digital survey model the survey responses are not anonymous but are treated confidentially. Answers are processed in such a way that the answers in the checkboxes cannot be attributed to the respondent. Participants are asked to refrain from documenting information in the comment fields that may be recognisable or traced back to them if they do not want it disclosed.

To reduce the burden for patients with more than one contact with a hospital/service and to ensure they are not asked to complete a survey too often, if randomly selected from the patient register to be surveyed, the person is exempted from being sent a questionnaire again for 9 months. The rule applied to selection is that an individual cannot get a questionnaire more frequently than every 10 months.

All psychiatric departments submit reports to the Danish National Patient Registry, from which the information is passed on to the Danish Psychiatric Central Research Register. The Danish Psychiatric Central Research Registry datasets are used to contact relevant survey participant through their digital mailbox to complete the specific mental health experience surveys for inpatient and outpatient services.

In the new digital LUP Psychiatry model people who use services were asked 10 national key questions. The national key questions are the same across the regions and cover for example, the involvement of people who use services and satisfaction with treatment. As with the previous survey model regions/hospitals and departments have the opportunity to choose a number of local questions themselves, which measure the part of the experiences of people who use services they are working to improve locally. The local questions are selected from a catalogue of tested and approved questions.

A department receives a monthly result if there are a minimum of five responses. For smaller units, responses need to be aggregated over several months to meet the reporting requirement.

Continuous data collection each month over the year, and the provision of real-time data supports ongoing quality improvement at regional/hospital, ward or at a section level (DEFACTUM, 2022).



The results from the ongoing measurements are collected for one month and reported to regions and departments the following month

Each region and hospital receives an annual report where the region can see the scores of the departments in relation to the region.

There is no longer a national report, it has been replaced by a one-page information sheet with the key national results.

There is a separate questionnaire for each of the two groups of people who use services for adult psychiatry (hospitalised patient and outpatient).

In 2023 the questionnaire was sent out to 34,224 adults who use services over 338 wards and outpatient clinics.<sup>(35)</sup>

The digital survey model is a four-week process, with two digital reminders.

This survey model of contact has yielded over a 25% response rate for 2023.

	Number of	Response
	responses	percentages
Overall response	9,501	28%
Outpatient adult patient	8,447 (29,922)	28%
Hospitalised adult patient	1,054 (4,302)	24%

Results of the 2023 monthly digital survey (over a 12 month period)

The national averages from the outpatient and hospitalised inpatient group from the 2023 digital survey model is different to previous survey models therefore data cannot be compared to previous years.

Data analyses was carried out using a 5 point scale, from 1 (not at all) to 5 (very much), 3 and below, 3.01 -3.50, 3.51-4.00, 4.00 and above

# Table 3: Data analysis of national average from the outpatient andinpatient groups

	Question	Ambulatory adults patient	Hospitalised adults patient	Overall (combined)
1	I am overall satisfied with my visit/ hospitalisation	4.02	3.33	4.00
2	A certain doctor takes overall responsibility for my overall course	3.68	3.15	3.66
3	The staff is friendly and welcoming	4.42	3.94	4.40



4	I can get in touch with the staff if necessary	4.04	3.70	4.03
5	The staff asks about my description of illness/condition	4.15	3.32	4.12
6	I help make decisions about examination/treatment	3.88	3.20	3.86
7	I get the information I need	3.89	3.28	3.87
8	I get help to deal with psychological difficulties	3.66	3.12	3.65
9	The staff talk to me about what I can do to get better	3.66	3.14	3.64

#### Lessons learned to date from the digital survey model

- The change to a digital survey model is only recent (2022) and so adjustment and learning is still ongoing.
- However, researchers have noted that sending out the survey soon after discharge that participants recall their experience better, and are more motivated to complete the survey (The digital survey model, is sent out the following month post discharge).
- If participants open the digital link they are more likely to complete the survey, however, many do not open the link at all in their digital post.
- The digital survey model provides a national representative sample of survey participants, is cheap to administer and has no evident bias, due to the randomised digital selection of survey participants.



## 5. Norway

#### Norway

The information outlined in this review was obtained from the Department for Research and Analysis of Health Services, Norwegian Institute of Public Health,<sup>12</sup> Oslo.

#### 5.1 Background

The total population of Norway is about 5.5 million, which is spread over nearly 400,000 square kilometres. Approximately 1.2 million people (22%) are under 18 years of age. Most of the population is concentrated in and around the major cities in the south of the country, Oslo (0.7 million), Bergen (0.3 million) and Stavanger (0.14 million) with Trondheim (0.21 million) in the middle of Norway. Dispersed throughout the north of the country which is over 1,000 miles in length from north to south are small towns and villages, leading to a largely scattered, remote widespread population.

The Norwegian healthcare system is based on the principles of universal access, decentralisation and free choice of healthcare provider. It is financed by taxation, together with income-related employee and employer contributions and out-of-pocket payments (co-payments). The responsibility for specialist care lies with the state, which is administered by four Regional Health Authorities (Northern, Central, Western, and South-Eastern Norway). Each region operates a number of public hospitals while municipalities are responsible for primary care. Private specialist health facilities are invited as partners to the system on a contractual basis.

In Norway, mental health asylums were established between 1865 and 1920 to provide care for those experiencing psychiatric/mental health issues. These have gradually been replaced by smaller hospitals and psychiatric wards in general hospitals. Commencing in the 1980s decentralisation and deinstitutionalisation of the long existing mental health asylums took place, with a dramatic decline in the number of hospital beds being provided and far greater emphasis and focus on the provision of outpatient services. Currently, 250,000 residents receive specialised mental healthcare services annually with most of these being treated in ordinary outpatient clinics. In line with other Western countries, the number of inpatient beds has been reduced, and the focus now is on care in the community. In Norway, as in other first world countries, opportunities for treatment, recovery, participation in society and care are more readily available today.

Norway operates a comprehensive secure national online portal healthcare system <u>https://www.helsenorge.no/en/</u>. Anyone who has a Norwegian personal identification number or an ID number can log in to Helsenorge. The Helsenorge site

<sup>&</sup>lt;sup>12</sup>The Norwegian Institute of Public Health (NIPH) contributes to quality improvement in the health services by summarising research, promoting the use of research results, measuring the quality of health services, and working to improve patient safety.



contains information about and access to health services for residents of Norway, messages, letters, appointments, referrals, medicines, test results, electronic health record from the hospital and vaccinations are all captured through the site.

The Norwegian Institute of Public Health (NIPH) has responsibility for conducting national experience surveys for people who use services in Norway.<sup>(36)</sup>

The Psychiatric Inpatient Patient Experience Questionnaire (PIPEQ)<sup>13</sup> is part of the Norwegian national programme for the measurement of experiences reported by people who use services reported experiences. The purpose of the programme is to systematically measure people's experiences of healthcare as a basis for quality improvement, healthcare management, and choice for people who use services and public accountability.

The first PIPEQ<sup>(37)</sup> model was carried out from 2005 to 2013. However, owing to the small numbers of patients per psychiatric institution, and even after receiving one reminder notifications four weeks later, the post-discharge mailed survey returned low response rates thereby, restricting the validity and usefulness of the results. The post-discharge surveys did not provide sufficient data to report robust quality indicators at psychiatric institutional level.

To address these challenges, a change from post-discharge to an on-site data collection was implemented from 2013 for psychiatric inpatient users. The Psychiatric Inpatient Patient Experience Questionnaire Onsite (PIPEQ-OS)<sup>(38)</sup> included most of the patient experience questions from the PIPEQ, with adjustments to account for the service users answering the survey in an on-site context and to ensure that it was in line with the national programme. The layout, formatting and structure was also updated. The PIPEQ-OS survey contained 44 questions (with an open comment field where people could tell more about their experiences from their stay to enhance the quantitative results). The questionnaire covered areas of care such as waiting time, admission, staff, the institution, information, the environment, and the range of activities, physical health and demographic background information.

The 2016 PIPEQ-OS survey was conducted as a cross-sectional survey, whereby all inpatient care adult psychiatric service users were surveyed on an agreed day and week only. While this survey had a 73% response rate; however, a limitation of applying this model was that the people using services included were at different stages of their treatment and care journey, with some people recently admitted for care and others receiving care for a longer period of time.

In 2019, The Ministry of Health and Care Services decided that the patient experience surveys among inpatient users in mental healthcare and treatment for substance dependence should be conducted as continuous electronic measurements from 2020. The measurements are still conducted on site, but as close as possible to

<sup>&</sup>lt;sup>13</sup> Psychiatric Inpatient Patient Experience Questionnaire (PIPEQ).



discharge. Previously developed and validated measures are applied. Beginning in January 2020 the NIPH started up with continuous electronic measurements of patient experiences with specialised mental healthcare and treatment for substance dependence. Previously developed and validated measures are still applied to the Psychiatric Inpatient Patient Experience Questionnaire – Continuous Electronic Measurement (PIPEQ-CEM).<sup>(39)</sup>

Table 4 provides an overview of the Psychiatric Inpatient Patient Experience Questionnaire – PIPEQ) which has evolved since its inception in 2005.

Year	Survey Name	Model
2005-2013	Psychiatric Inpatient Patient Experience Questionnaire (PIPEQ)	Post discharge, postal survey
2013- 2019	Psychiatric Inpatient Patient Experience Questionnaire – On Site (PIPEQ-OS)	On site data collection on a specific selected day and date (one day only APPROACH)
2020 onward	Psychiatric Inpatient Patient Experience Questionnaire – Continuous Electronic Measurement (PIPEQ- CEM)	Continuous electronic measurement, on site, each patient is invited to participate as close as possible to the time of discharge from care

# Table 4: Overview of the Psychiatric Inpatient Experiences Questionnairesdeveloped.

#### 5.2 Objective

In Norway, national performance measures are used in quality improvements, for managing healthcare institutions and for public accountability and patient choice.

The objective was to develop and implement a validated survey model to learn about psychiatric inpatient experiences of care following their admission, treatment prior to discharge from psychiatric institutions. The purpose of the survey is to systematically measure people's experiences and satisfaction within the services.



#### **5.3 Commitment**

The national psychiatric inpatient experience survey has been developed and implemented by the Norwegian Institute of Public Health with commitment and support from the Ministry of Health and Social Care Services and across the healthcare sector. The national survey is financed by the Norwegian Directorate of Health. Different models of psychiatric patient experience surveys (PIPEQ, PIPEQ – OS and the new electronic version PIPEQ-CEM) have been developed and modified since the first post discharge survey was carried out in 2005.

As of 1 January 2020, the Ministry of Health and Social Care (HOD) and the Directorate of Health (Hdir) commissioned the Norwegian Institute of Public Health (FHI) to commence ongoing, electronic measurements of user experiences within mental healthcare (PHV). The Ministry of Health and Social Care stipulates that regional health organisations must ensure that psychiatric inpatient health organisations participate in the ongoing survey.

#### **5.4 Data protection (Ethics and data protection impact assessments)**

The Norwegian Institute of Public Health (NIPH) (Norwegian: Folkehelseinstituttet; FHI) is a government agency and research institute, under the Ministry of Health and Care Services. NIPH acts as a national competence institution in public health, the institute's main activities are health surveillance, research and disease prevention.

The national PIPEQ-CEM is conducted as an anonymous quality assurance project and according to the joint body of the Norwegian Regional Committees for Medical and Health Research Ethics, research approval is not required for quality assurance projects. The Norwegian Social Science Data Services states that anonymous projects are not subject to notification. The NIPH Data Protection Officer and the Research Director of the healthcare services division has assessed and formally approved the survey.

The standard procedure in all patient experience surveys conducted by the Norwegian Institute of Public Health is that returning the completed questionnaire constitutes patient consent.

The responsible professional at the psychiatric institutions are permitted to exclude vulnerable patients for special ethical reasons, in line with the Declaration of Helsinki.

#### 5.5 The PIPEQ – CEM survey (piloted) Survey sample

The survey population includes all adult inpatients who received specialised care in a psychiatric institution/unit and who are 18 years or over.

In Norway specialised mental healthcare is organised under four health regions, with underlying hospital trusts. All public and private residential institutions with a



contract with regional health authorities were included in the survey, some of which are standalone institutions and some are units organised under a hospital.

#### 5.6 Distribution and collection

Employees at the psychiatric institutions recruit people who use services to the national survey as close to the time of discharge as possible. Patients are invited to reply using an electronic version of the questionnaire. The PIPEQ-CEM survey is carried out electronically.

Institutions have purchased iPad's to facilitate patients to complete the questionnaire. Telephones, and computers can also be used and employees provide the log in code. This allows on site, self-reporting with no identifiers required.

The NIPH is responsible for planning and coordinating the data collection, and compilation and reporting of the PIPEQ-CEM survey findings

#### 5.7 Communication

The NIPH organised regional contact persons to help compile the institutions list and help establish contact persons at the health authority, health trust, institutional, department and section level. A project manager was assigned to each participating unit with tasks including disseminating information to the patients and employees, distributing login information to people who use services, and reporting the progress of the survey to NIPH.

On logging in to the Helsenorge.no platform participants receive information and comprehensive messages about the PIPEQ-CEM electronic study and are directed to the survey for completion.

#### 5.8 Response Rate

Currently the PIPEQ-CEM continuous electronic version is in its pilot stage.

For the first year of the continuous measurements from psychiatric institutions in Norway, from 1 January 2020 to 31 December 2020 included 191 different sections and 3,249 service user responses. 58.3% were female, 63.8% were 18 to 44 year olds, 32.4% had been educated to a university or college level, 29.1% were married or living with a partner, 89.3% were born in Norway, and 43.1% had three or more previous admissions. The duration of stay for 25.8% of participants was more than four weeks.

The large national sample included responses from 70% of all inpatient units in Norway.

#### 5.9 Survey Questionnaire

The current piloted PIPEQ-CEM survey questionnaire<sup>(40)</sup> is similar in structure to the PIPEQ-OS and consists of 46 closed-ended individual questions.

With a free text field where the patients can write more about their experiences



The survey is designed in 11 sections, following the pathway of care. The sections include

- Waiting time and admission
- Therapists and staff
- Involvement at the institution
- Information
- Environment and activities
- Negative events/incidents
- Other assessments
- Follow-up of physical health
- Help from the municipality
- Overall assessment of the health services
- A little about you and your background.

#### 5.10 Analytical methodologies

Of the 46 closed ended questions, 21 items address inpatient experiences and the care is scored using a 5 point response scale ranging from 1 ("not at all") to 5 ("to a very large extent"). The 5 point response scale was chosen by the NIPH to be consistently applied in the surveys to make it possible to make comparisons over time and potentially between different healthcare patient groups.

The results are easier to interpret and use because the patients answer at the same place in the process.

The data collection is carried out electronically using the TSD Netskjema from the University of Oslo.

Analyses is performed using SPSS (version 22.0).

The vast majority of questions, are arranged so that high values represent positive answers, and conversely low values represent negative answers.

The main aim of the survey was to compare results between different healthcare services rather than informing decision-making or evaluating operational management services.

#### 5.11 Outputs

Due to the small sample size in institutions, continuous measurement, makes it possible to achieve an acceptable sample size, thereby allowing institutions to receive their own detailed results, instead of aggregated on a higher level in the healthcare system.

The PIPEQ-CEM results are published only weeks after the reporting period and reports are distributed to all units with a sufficient number of response. Five responses are needed to receive individual reports.



The Norwegian Institute of Public Health make tabular quarterly reports with descriptive results available for units that have sufficient number of respondents.

The NIPH provide hard copy reports at individual institution level, department level, and health trust level.

An annual national report is provided in which overall results for participating units are compiled.

#### 5.12 Impact

This is one of the first of its kind in continuous measurement of healthcare experiences for those who use services. Findings are used for research and quality improvements within individual institutions.

Changing the data collection mode to a purely electronic strategy reduced costs and required shorter data collection periods.

The PIPEQ-CEM provides feedback in specific areas and the results are used to monitor performance and identify departments where quality can be improved from the patient's perspective.

Given that this is still a pilot project, it is expected that the interpretation and comparison of the data will be easier as people who use services will be in the same phase in their clinical pathway, and the hope is that the data will be more beneficial for health and social care staff to identify areas of quality improvements.

#### 5.13 Key recommendations and lessons learned

- A major disadvantage of an on-site survey model is the burden associated with recruiting and completing the survey for employees at the psychiatric institutions.
- Following implementation of the PIPEQ-CEM employees at institutions raised concerns regarding the cognitive abilities and motivation of people using services and emphasised the need for a shorter questionnaire that is appropriate for people with a wide range of literacy levels.
- PIPEQ-CEM represents an innovative, feasible and time effective approach to collecting large scale data and rapidly reporting responses using web-based administration methods.
- This model required establishing points of contact at all levels, establishing new routines for data collection and continuous communication is necessary between the NIPH and each institution to report on how the data collection is progressing.
- To obtain representative data all people who use services should be invited to participate.
- This model does not include measurements of user-reported experiences or outcomes following discharge. The potential for a combination of an on-site



approach with a post discharge postal approach for outpatient users is recommended.

- Research indicates that on site survey approaches may increase response rates but the results are more favourable compared to mailed surveys.
- A limitation of web based surveys is that they can exclude those with poor digital literacy.
- No information was captured or documented about non respondents or overall number of eligible participants.

Issues arise with poor numbers responding, related to both provider level factors (providers fail to recruit people who use services to the survey) and patient level factors (for example, respondent burden, language problems). Research and development plans are in place to address these issues such as:

- The development of a shorter and more user-friendly questionnaires.
- Translated into the most common foreign languages used by people who use mental health services.
- The establishment of a new system for recruitment into the surveys on site.
- Develop outcome measure for community services, and for post discharge patients.
- Obtain background data from the Norwegian Patient Registry to enable postdischarge surveying of people using services to complement the on-site survey.



# 6. England

The information outlined in this review was obtained from conversations with Caroline Killpack, Head of Survey Coordination, Survey Coordination Centre, Picker Institute Europe<sup>14</sup> based in Oxford England.

The review focuses on the Community Mental Health Survey (CMH) carried out by the Survey Coordination Centre for Existing Methods (SCCEM) at Picker, on behalf of the Care Quality Commission (CQC).<sup>15</sup> The survey has been carried out almost every year since 2004 as part of the National Health Service (NHS) Patient Survey Programme (NPSP).

#### 6.1 Background

The United Kingdom has a total population of roughly 68 million people, with England having the largest share of this at 57 million. The median age of the population is just over 40 years of age.<sup>(41)</sup> Most healthcare in England is provided by the NHS, England's publicly-funded healthcare system. Social care services are a shared responsibility between the local NHS and the local government's Directors of Social Services, and falls under the guidance of the Department of Health.

Mental health support for adults in England is provided by NHS organisations, voluntary and community sector initiatives, local authorities and independent providers. Care is provided in primary care (for example by the GP), in the community by mental health teams, in hospitals and in specialist services. These services are described as primary, secondary and tertiary care. Community mental health services, also referred to as 'secondary services', are made up of multidisciplinary teams that include a range of professionals such as nurses, occupational therapists, social workers, psychologists and psychiatrists.

Community mental health services play a crucial role in the delivery of mental healthcare, providing vital support to people with mental health problems closer to their homes and communities

In recent years, government mental health policy has focused on reforming mental health services. A key priority has been to reduce the pressures on inpatient care, with policy-makers highlighting the potential for community services to play an integral role in achieving this. The NHS Long Term Plan published in 2019<sup>(42)</sup>

<sup>&</sup>lt;sup>14</sup> Picker Institute are a leading healthcare charity who research patient and staff experience of care. They work with NHS trusts, government, charities, academia and commercial organisations.

<sup>&</sup>lt;sup>15</sup> The Care Quality Commission (CQC) is the independent regulator of health and social care services in England.



provides structure for NHS service reform, and it builds on the commitments set out in the Five Year Forward View for Mental Health.<sup>(43)</sup>

The NHS Long Term Plan set out an objective to redesign community mental health services as place-based, integrated services that bring together primary and secondary mental health care to provide a core community service, aligned with primary care networks, for people with any level of mental health need.

In 2019, NHS England and NHS Improvement (now NHS England) and the National Collaborating Central for Mental Health (NCCMH) published a community mental health framework for adults and older adults.<sup>(44)</sup> The purpose of the new framework was to ensure a minimum universal standard of care for everyone in need of community mental health services. The framework places community mental health services in the centre of the community, as the central pillar of mental healthcare, thereby allowing all other services in the mental healthcare system to function more effectively.

The Care Quality Commission (CQC) is the independent regulator of health and adult social care services in England. Its role is to ensure that health and social care services provide people with safe, effective, compassionate, high-quality care and they encourage care services to improve. The CQC monitors, inspects and regulates services and publishes its findings.

All eligible NHS trusts in England participate in the NHS Patient Survey Programme, asking people who use services their views on their recent healthcare experiences. The findings from these surveys provide organisations with detailed patient feedback on standards of service and care, and can be used to help set priorities for delivering a better service for people who use services. The survey results are also used by the CQC to measure and monitor performance at both local and national levels.

The NHS Patient Survey Programme (NPSP)<sup>16</sup> collects feedback on adult inpatient care, maternity care, children and young people's inpatient and day services, urgent and emergency care, and community mental health services. The NPSP is commissioned by the CQC.<sup>17</sup>

<sup>&</sup>lt;sup>16</sup> The NPSP is a survey programme comprising of 5 self-completion surveys, Adult Inpatient user, Maternity, Children and Young People's Patient Experience Survey, Urgent and Emergency Care Survey and Community Mental Health Survey. The surveys in the programme are commissioned by the CQC and administered by coordination centres (at Ipsos and Picker Institute).

<sup>&</sup>lt;sup>17</sup> To learn more about the CQC's survey programme, you can visit the CQC website at <u>https://www.cqc.org.uk/publications/surveys/surveys</u>



As part of the NPSP, the Community Mental Health Survey was established in 2004. The survey asks people who use NHS community mental health services in England about their experiences of care.

In 2023, the Community Mental Health Survey underwent a large-scale redevelopment, revising the methodology, eligibility and questionnaire design. This included lowering the eligibility age to now include 16 and 17-year-olds.<sup>18</sup> The sample period and duration also changed from September to November, to the months of April and May. In addition, 23 new questions were added, 19 were removed, and 14 were amended. As a result of the changes, it is not possible to compare the results from the 2023 survey with data collected in previous years.

For the first time, participants of the 2023 survey were also offered the choice of responding online or via a paper-based questionnaire.

#### 6.2 Objective

The purpose of the community mental health survey is to understand, monitor and improve the experiences of people who use NHS community mental health services. Data collected from the Community Mental Health Survey is used by the CQC in its assessment of mental health trusts in England. The results are also used by NHS England and NHS Improvement and the Department of Health and Social Care (DHSC) for performance assessment, improvement, governance and regulatory purposes.

#### 6.3 Governance arrangement

The Survey Coordination Centre (SCC) based at Picker, manage and coordinate the Community Mental Health Survey as part of the NHS Patient Survey Programme (NPSP), on behalf of the Care Quality Commission (CQC).

The survey has run every year since 2004 as part of the NHS Patient Survey Programme (NPSP), with the exception of 2009 when a survey of mental health inpatients was run. The purpose of the survey is to understand, monitor and improve people's experiences of NHS community mental health services.

#### 6.4 Commitment

The NHS outcomes framework (Domain 4) recognises the importance of delivering high-quality services to encourage positive service user experiences. With this in mind, the NHS Constitution<sup>(45)</sup> commits the NHS to collecting feedback from patients, noting that information collected should be used for service improvement. The

<sup>&</sup>lt;sup>18</sup>The NHS Long Term plan has committed to improve access to community-based mental health services to meet the needs of an additional 345,000 children and young people aged 0-25 by 2024. The change in the eligibility criteria to include 16- and 17-year-olds resulted from an appetite to understand the experience of transition from Children and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS).



Health and Social Care Act 2012<sup>(46)</sup> emphasise the importance of patient's involvement in health and social care, stating that commissioners of services must encourage and enable people who use services, and their carers, to make decisions about their care and treatment.

The Care Quality Commission (CQC) places people and communities at the centre of its strategy for health and social care,<sup>(47)</sup> stating that regulation will be driven by people's experiences of care and focusing on what is important to them as they access and navigate services. As part of CQC's single assessment framework, people's experiences of services are a key evidence category which is used to inform the rating of health and social care services.

#### 6.5 Data protection

Survey participants' personal data are held in accordance with the General Data Protection Regulation and the NHS Confidentiality Code of Practice. Survey answers are not linked to participants name, phone number or full address, but researchers analysing the results of the survey will use participants' postcode to undertake geographical analysis of overall results.<sup>(48)</sup>

Under Section 251 of the National Health Service Act 2006<sup>(49)</sup> allows patient data to be shared outside of NHS trusts without gaining prior and explicit consent from these patients.

The CQC adheres to its Information Governance Policy.<sup>(50)</sup> The policy defines the Care Quality Commission's (CQC) approach to Information Governance. It provides assurance that its practices comply with legislation and CQC's business requirements, and that information risks are appropriately recognised and managed.

Prior to submitting their sample, trusts have to complete a community mental health survey declaration form to help reduce sampling errors.<sup>(51)</sup> This form outlines a number of required checks to ensure that the sampling instructions have been followed correctly. It also helps to confirm that trusts have maintained patient confidentiality by taking the steps laid out in the sampling instructions, such as only sharing the required variables. Approval of this form by a trust's Caldicott Guardian<sup>19</sup> prior to data submission not only fulfils the trust's requirements under the Data Protection Act 2018 (the data protection legislation which the 2023 Community Mental Health Survey was subject to), but also reduces the potential for breaches to

<sup>&</sup>lt;sup>19</sup> The Caldicott Guardian provides advice and oversight to ensure that confidential personal information relating to people who use the services regulated by the CQC is obtained, used, handled and shared in accordance with the Caldicott Principles.



the support received under Section 251 of the NHS Act 2006. Participation in the survey is voluntary and all information is anonymous.

#### 6.6 Ethical approval

NHS organisations in England follow a process of seeking approval to undertake research.<sup>(52)</sup> Although, the NPSP is considered a service evaluation and therefore does not require approval, every survey within the programme applies for ethical approval to comply with best practice.

All the changes made to the NHS Community Mental Health Survey in 2023 (questionnaire, covering letters and so on) will have received ethics approval.

#### 6.7 The survey The sample

For the 2023 community mental health survey all trusts were required to submit a random sample of 1,250 people who use services as a minimum, however trusts could choose to boost their sample and include additional records.

Eligibility criteria for people to take part in the survey was:

- Be aged 16 years and above
- Seen by someone face-to-face at the trust or via video conference or telephone call between 1 April and 31 May 2023 (the sample period)
- And had at least one other contact (face-to-face, video conference, phone or email) either before, during or after the sampling period.

Exclusion criteria included:

- People under the age of 16 years old at the time of drawing the sample.
- People known to have died.
- People known to be current inpatient users at the time of drawing the sample.
- Users that did not have a known UK address.
- People were removed if there was insufficient name or address information for the questionnaire to have a reasonable chance of being delivered.

#### 6.8 Distribution and Collection

For the first time since its inception, the 2023 survey has been conducted using a mixed mode approach of online questionnaire followed by a paper questionnaire being mailed to non-respondents. Participants had the option to complete the questionnaire online before being offered the option of a paper questionnaire.



# Table 5. The contact approach for the 2023 Community Mental HealthSurvey

Schedule	Contact type
Week 1 (day 0)	Letter with URL and log in details for online survey
Week 2 (day 7)	SMS with unique link to online survey (if phone number available)
Week 3 (day 14)	Letter with URL and log-in details for online survey AND paper questionnaire
Week 4 (day 21)	SMS with unique link to online survey (if phone number available)
Week 5 (day 28)	Letter with paper questionnaire only

Invitation letters were sent to patients' home addresses, offering the option to complete the questionnaire online, the letter outlines why the survey is being conducted and the importance of feedback.

Patients were sent two letters containing a URL for the online survey, and two SMS reminders with a personalised URL that takes them directly into the online survey without a login required, to encourage online completion.

SMS reminders were sent at different times of day to reach different groups. The first SMS should be sent between 9am and 10am, seven days after the initial contact.

The second SMS should be sent between 4pm and 5pm, seven days after the second contact. (SMS) reminders contained a unique link to the online survey.

All participants received a postal questionnaire alongside their third letter.

Fieldwork for the survey (the time during which questionnaires were sent out and returned) took place from the 18 August 2023 to 1 December 2023, and the fieldwork period was shortened from 18 to 15 weeks (following a review process and redevelopment of the survey).

The online survey was translated into nine non-English languages (Arabic, Bengali, French, Gujarati, Polish, Portuguese, Punjabi, Spanish, and Urdu) and British Sign Language. Additionally, participants were able to change font size, background colour of the online survey and it was tested to ensure screen reader compatibility. The paper version is available in Braille, large-print and easy to read formats on request.



Participants can request a telephone assisted complete in English or in a non-English language using the helpline provided.

#### 6.9 Communication and publicity

A number of materials were produced to inform and advertise the survey to service users such as information leaflets, frequently asked questions (FAQs) leaflet, posters with different backgrounds, and social media cards to be displayed during the sampling period.

A dissent poster was created for display during the sampling period. This was intended to make patients aware of the survey and provide an opportunity for them to ask questions or opt out if they wished to be excluded from the survey.

To target the 16 and 17-year-old survey population, a specific leaflet included significant information on the purpose of the survey, options to give dissent, data protection and confidentiality was developed and displayed on NHS Trust websites.

Two press release templates were designed and shared with NHS Trusts and national organisations, providing information about the purpose and value of the survey which allowed trusts to emphasise how they have used previous survey results for improvement. For national organisations, the template includes national level results of the survey.

Four social media cards were developed to promote engagement prior to and during fieldwork. Trusts and third sector organisations were asked to share these on their social media pages at different stages of the fieldwork period. The cards provide basic information about the survey including the purpose, value, when people who use services will be invited and how to participate. They were designed for easy use across a number of platforms including Twitter/X, LinkedIn, Facebook, and Instagram.

A publicity activities plan was implementation to publicise the survey and increase engagement at national and local levels. Trusts and mental health charities were asked to promote the survey on their communication networks via a series of engagement activities which included: posters, information leaflets, social media cards, banners and information was included on NHS trusts websites.

#### 6.10 Response rates

The sample size for the survey was a minimum of 1,250 participants per trust; of which there were 53. Seven trusts provided a boosted sample (between 1,750 and 5,000 service users). This provided a total combined sample size of minimum 74,988 people who use services across England. Overall, there were a total of 14,770 responses (7,527 online responses and 7,052 paper responses) from people who



received treatment for a mental health condition between 1 April and 31 May 2023, giving a 20% response rate.

Responses were received from 11,163 Adult Mental Health Service (AMHS) users and from 873 Child and Adolescent Mental Health Service (CAMHS) users. Survey responses were also received from 2,734 Older Peoples' Mental Health Service (OPMHS) users.

The 2023 survey findings showed that people's experiences of NHS community mental health services are poor, with less than half of all respondents (39%) saying they were 'definitely' given the help they needed the last time they saw someone. In addition, half of all respondents (50%) were not always given enough time to discuss their needs and treatment.

Basic demographic information was collected from everyone who took part in the survey. The demographic data shows a balanced respondent profile in terms of age, with a lower representation of respondents over 81 years old. 61% of respondents were females and when ethnic group respondents were mostly white (87%).

#### 6.11 Analytical methodologies

The survey questionnaire was made up of 49 questions to include nine demographic questions and three separate free text questions to include any other information not included in the questionnaire.

The survey was designed into 10 sections:

- Your NHS appointments
- Accessing care and treatment
- Your mental health team
- Your care
- Your treatment
- Crisis care
- Support and wellbeing
- Overall care
- About you
- Three free text sections for other comments.

Survey findings were categorised under 13 themes, these included support while waiting, mental health team, planning care, involvement in care, medication, NHS talking therapies, crisis care support, crisis care access, support with other areas of life, support in accessing care, respect, dignity and compassion, overall experience and feedback.

The questions were mainly structured closed-ended questions.



Questions are scored on a scale from 0 to 10. The scores represent how positive people's experiences were. A score of 10 is assigned to the most positive experience possible, whereas a score of 0 is assigned to all responses that reflect considerable scope for improvement.

Data was suppressed for questions which have fewer than 30 Trust-level responses post-cleaning. The procedure of data suppression is implemented across the NPSP to protect against respondents potentially being identified and because the confidence interval around the Trust's question score is considered too large to be meaningful.

The report demonstrates that people's experiences of NHS mental health services provided in the community are poor. Most notably around quality of care, crisis care, support while waiting, planning and involvement in care, and support with other areas of life.

#### 6.12 Outputs

The survey results are published in benchmark reports<sup>(53)</sup> for each individual trust, and are available on the NHS Surveys website. The reports includes key trust-level findings relating to the people who took part in the survey, a section providing an overview of results for each trust, identifying areas where the organisation performs better than the average and where the trust may wish to focus improvement activities.

Benchmarking – shows how each trust scored for each evaluative question in the survey, compared with other trusts that took part and shows the range of scores achieved and allows trusts to compare themselves with the other organisations that took part in the survey.

National level results were collated according to the three main Assessment Group types: Children and Adolescent Mental Health Services (CAMHS), Adult Mental Health Services (AMHS), Older People Mental Health Services (OPMHS).

#### 6.13 Impact Care Quality Commission (CQC)

CQC use the survey results to build an understanding of the risk and quality of services and those who organise care across an area. Where survey findings provide evidence of a change to the level of risk or quality in a service, provider or system, CQC will use the results alongside other sources of people's experience data to inform targeted assessment activities.

#### NHS trusts and commissioners

Trusts, and those who commission services, use the results to identify and make the changes they need to improve the experience of people who use their services.



#### **NHS England**

NHS England is a key user of data from the NHS Patient Survey Programme. Listening to service users experiences of their care plays a crucial part in delivering services that are safe, effective and continuously improving.

CQC data supports NHS England to track how it is doing on patient experience, and understand where inequality is present and the impact that policy initiatives are having on people who use services.

#### **Department of Health and Social Care**

The government measures progress on improving people's experiences through Domain 4 of the NHS Outcomes Framework 'ensuring people have a positive experience of care'. The Framework sets out the outcomes and corresponding indicators that the Department of Health and Social Care uses to hold NHS England to account for improvements in health outcomes.

#### Key recommendations and lessons learned

- As a result of the changes to the 2023 Community Mental Health Survey, it
  was not possible to compare this year's results with data collected in previous
  years. Future iterations will need to be completed for comparisons of data.
- In determining the sample period for the survey, seasonal effects should be considered. The sampling period for the Community Mental Health Survey was changed to April and May 2023. Previous surveys had taken place from September to November.
- Throughout this questionnaire, people who use services were asked to reflect on their experience over the last 12 months; however, it is important to recognise the possibility of recall bias occurring, if people who use services were unable to accurately remember their mental health experiences or if patients had not maintained contact with services.
- Response rates have declined for the community mental health survey since it commenced in 2004. Changing to a mixed model has increased the response rates in other surveys and the hope is it will also be similar with this survey.
- Moving from a solely paper based survey to a mixed model approach has the potential to make the survey more cost-effective by decreasing postal responses, saving money on return postage, processing paper returns and paper storage.



## 7. Appendices

#### Appendix 1: Participants and organisations that contributed to this review

The Project Lead on behalf of the National Care Experience Programme would like to thank the below participants and organisations for generously giving their time and knowledge to inform this international review.

Date of Contact	Name	Title/Position	Organisation	Country
October 2023	Simone Witzel	Chief Consultant	DEFACTUM	Denmark
October 2023	Hilde Karin Hestad Iversen	Senior Researcher, PhD	Department for Research and Analysis of Health Services, Norwegian Institute of Public Health	Norway
September 2023	Emma McKeown	Executive Director, Insight, Performance and Digital Services	North Western Melbourne Primary Health Network	Australia
September 2023	Caroline Shelton	Service Delivery Manager, Head to Health,	North Western Melbourne Primary Health Network	Australia
September 2023	Jagjit Dhaliwal	Executive Director, Service Development & Reform	North Western Melbourne Primary Health Network	Australia
January & April 2024	Caroline Killpack	Head of Survey Coordination, Survey Coordination Centre,	Picker Institute Europe	England



#### Appendix 2: Summary Table of International Review Findings

Jurisdiction	Survey	Setting	Sample / population	Methodology	Response rate	The questionnaire	Outputs
Australia	Head to Health (H2H) Initial Intake Experience Survey	<b>Community</b> - H2H Centres and satellite networks of community based adult mental health services to be delivered by multidisciplinary teams, providing holistic, collaborative care embedded into existing primary care settings.	Every person who contacts the Head to Health phone service, or who walks into a H2H service/hub	Online - Administered day after intake Following consent at the point of referral, A link is sent to consumers by SMS or email to complete the survey.	22% since July 2022	<ul> <li>13 questions, broken into four sections. The sections include questions on:</li> <li>Why the consumer contacted H2H</li> <li>What their intake experience was like</li> <li>A free text box to describe how their experience could have been better and</li> <li>A section on consumer demographics</li> </ul>	A reporting portal/ dashboard is provided and it is made available to Primary Health Networks and service providers to enable survey responses can be viewed and analysed in real time. In addition to having access to the secure portal, PHNs and service providers receive regular reports.
Australia	Head to Health Your Experience of Services (YES) Primary Health Networks Mental Health Survey	<b>Community</b> - The survey asks about experiences of care received in a community service in the	All consented consumers exiting the service or after three months of care, whichever comes first.	Online - A link is provided by SMS or email to complete the survey.	Where PHNs use the aggregated results for quality improvements, a 50% response rate (of those offered the	<ul> <li>26 questions including questions on</li> <li>Experience of care</li> <li>How well the service did</li> </ul>	A specialised patient reporting software company works with providers to report the findings.



Dennes		previous three months or less.	Consumers experiencing an acute episode are not included.	Quilling	survey) is considered desirable.	Debugen 25	The week's C
Denmark	Landsdækkende Undersøgelse af Patientoplevelser (LUP) "Nationwide Survey of Patient Experiences" Psychiatry	People who use adult <b>inpatient</b> <b>and outpatient</b> mental health (not forensic mental health) <b>Surveys are</b> <b>carried out on</b> <b>5 Patient</b> <b>groups:</b> • Adults (hospitalised /inpatient) • Adults (ambulatory/ outpatient) • Children and youths (under 11 years) • Children and youths (12- 18 years) • Specialised Forensic Psychiatry inpatient users – (shorter	Since 2022, a monthly digital survey model is in place. Eligibility for the ambulatory / outpatient survey group required patients to have had contact with one or more therapists in outpatient adult psychiatry services, and must have had at least three personal contacts in the current period.	<b>Online</b> - Participants are identified through the psychiatric registers (patient information/enc ounters is completed by the hospital/service into the registers) and invited to complete the surveys through their individual's digital mail box	2021 response rates (pre digital model): Hospitalised patient: 66% Ambulatory / outpatient; 61%	Between 25 and 35 questions. Nine national questions across surveys include: reception/visit or admission, staff, treatment, patient and relative involvement, coercion during hospitalisation, coherence and collaboration, discharge and overall impression.	The results for LUP Psychiatry are reported nationally and at regional, departmental/ho spital and unit level. Results are available to the public on the official portal for the Danish healthcare services.



Norway							
	Psychiatric	<ul> <li>parents are asked to complete survey along with input from child (where appropriate</li> <li>Parents of children and youths aged 12-18 years are asked to complete a separate survey</li> <li>Inpatient -</li> </ul>	Includes all adult	Online –	From 1 <sup>st</sup> of	46 closed-ended	The PIPEQ-CEM
		questionnair e) Surveys are carried out on 4 Relative groups: • Relatives of hospitalised adults (every three years) • Relatives of out-patient adults (every three years) • If a child is under 11 years,	Relatives of adult patients are eligible to participate however, the patient decides which relative / caregiver they wish to participate.				



	Experience Questionnaire – Continuous Electronic Measurement (PIPEQ-CEM)	Adult inpatient who received specialised care in a psychiatric institution/unit and who are 18 years or over.	received specialised care in a psychiatric institution/unit and who are 18 years or over. All public and private residential institutions with a contract with regional health authorities were included in the survey Eligible participants are identified by staff at local level institutions	Employees at psychiatric institutions recruit patients to the national survey as close to the time of discharge as possible. Patient are invited to reply using an electronic version of the questionnaire. Institutions provide iPad's, telephones and computers to facilitate patients to complete the questionnaire. This allows on site, self- reporting with no identifiers required.	31 <sup>st</sup> December 2020, 3,249 patient responses were received The large national sample included responses from 70% of all inpatient units in Norway.	questions with a free text field where patients can write more about their experiences. Survey is designed in 11 sections, following the pathway of care: Waiting time and admission, therapists and staff, involvement at the institution, information, environment and activities, negative events/incidents. Other assessments, follow-up of physical health, help from the municipality, overall assessment of the health services and a little about you and your background.	published only weeks after the reporting period and reports are distributed to all units with a sufficient number of response. The NIPH provide hard copy reports at individual institution level, department level and trust level. An annual national report is provided in which overall results for participating units are compiled.
England	Community	Community –	All NHS Trusts	Mixed mode	From between	The survey	The survey
	Mental Health Survey (CMH23)	The survey asks people who use	were required to submit a random	approach a link and QR code is	the 1 of April and 31 of May	questionnaire was made up of 49	results are published in



	NHS community mental health services in England about their experiences of care.	<ul> <li>sample of 1,250 service users as a minimum.</li> <li>Eligibility criteria for service users include: <ul> <li>Be aged 16 years and above</li> <li>Be seen by someone face-to-face at the trust or via video conference or telephone call between 1 April and 31 May 2023</li> <li>Had at least one other contact (face- to-face, video conference, phone or email) either before, during or after the sampling period.</li> </ul> </li> </ul>	provided in the postal invitation letter to an online questionnaire followed by a paper questionnaire being mailed to non- respondents Or the option to request a paper hardcopy questionnaire QR codes are displayed on posters (link to online survey questionnaire)	2023, there was a 20% response rate.	questions to include 9 demographic questions and 3 separate free text questions to include any other information not included in the questionnaire. The survey was designed into 10 sections: • Your NHS appointments • Accessing care and treatment • Your mental health team • Your care • Your treatment • Crisis Care • Support and well being • Overall care • About you • 3 Free text sections for other comments	benchmark reports for each individual trust and are available on the NHS Surveys Websites National level results were collated according to the three main Assessment Group types: Children and Adolescent Mental Health Services (CAMHS), Adult Mental Health Services (AMHS), Older People Mental Health Services (OPMHS).
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### References

1. Sarah Greene. A Framework for Making Patient-Centered Care Front and Center. *The Permanente Journal*. 2012. Available from: <u>https://dx.doi.org/10.7812/tpp/12-025</u>.

2. Carrie Janerka, Gavin D. Leslie, Fenella J. Gill. Development of patient-centred care in acute hospital settings: A meta-narrative review. *International Journal of Nursing Studies*. 2023; 140:[104465 p.]. Available from:

https://www.sciencedirect.com/science/article/pii/S0020748923000305. Accessed on:

3. Michelle Beattie, Douglas J. Murphy, Iain Atherton, William Lauder. Instruments to measure patient experience of healthcare quality in hospitals: a systematic review. *Systematic Reviews*. 2015; 4(1). Available from: <u>https://dx.doi.org/10.1186/s13643-015-0089-0</u>.

4. Cathal Doyle, Laura Lennox, Derek Bell. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open*. 2013; 3(1):[e001570 p.]. Available from: <u>https://dx.doi.org/10.1136/bmjopen-2012-001570</u>.

5. Karen Luxford, Sue. Sutton. How does patient experience fit into the overall healthcare picture? . *Patient Experience Journal*. 2014; 1(1):[21 p.]. Available from: https://dx.doi.org/10.35680/2372-0247.1002.

6. Rashid Al-Abri, Amina Al-Balushi. Patient Satisfaction Survey as a Tool Towards Quality Improvement. *Oman Medical Journal*. 2014; 29(1). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3910415/#:~:text=Patients'%20evaluation %20of%20care%20is,benchmarking%20across%20the%20healthcare%20institutions.

7. Department of Health. *Department of Health Statement of Strategy 2023-2025*. Department of Health. 2023. Available from: https://www.gov.ie/en/publication/49239-department-of-health-statement-of-strategy-2023-2025/.

8. Department of Health. *Sharing the Vision A Mental Health Policy for Everyone*. Department of Health: 2020. Available from: https://www.hse.ie/eng/about/who/mentalhealth/sharing-the-vision/.

9. Department of Health. *National Cancer Strategy 2017-2026*. Department of Health. 2017. Available from: <u>https://www.gov.ie/en/publication/a89819-national-cancer-strategy-2017-2026/</u>.

10. Department of Health. *Sláintecare Implementation Strategy*. Department of Health. 2018. Available from: <u>https://www.gov.ie/en/publication/6011cf-slaintecare-implementation-strategy/</u>.

11. Department of Health. *Sláintecare Implementation Strategy and Action Plan 2021-2023*. Department of Health. 2021. Available from:

https://www.gov.ie/en/publication/6996b-slaintecare-implementation-strategy-and-action-plan-2021-2023/.

12. National Care Experience Programme. *The National Patient experience Survey*. 2017.



13. Yourexperience.ie. *Listening, Responding and Improving. The HSE response to the findings of the National Patient user experience Survey.* 2018. Available from: https://yourexperience.ie/wp-content/uploads/2021/10/NPES National QIP 2018.pdf.

14. HSE. *HSE Psychosocial Response to the Covid-19 Pandemic*. HSE. 2020.

15. Amhocn *Your Experience of Service Primary Health Networks survey sample PDF* [Online]. Available from

https://www.amhocn.org/\_\_data/assets/pdf\_file/0017/700451/yes\_phn\_survey\_sample.pdf.

16. Australian Bureau of Statistics *National Study of Mental Health and Wellbeing* [Online]. Available from <u>https://www.abs.gov.au/statistics/health/mental-health/national-study-mental-health-and-wellbeing/latest-release#cite-window1</u>. Accessed on:

17. State of Victoria *Royal Commission into Victoria's Mental Health System, Final Report, Summary and recommendations, Parl Paper No. 202, Session 2018–21* 

(document 1 of 6) [Online]. Available. Accessed on:

18. Australian Commission on Quality and Safety in Healthcare ACQSHC *National Safety* and *Quality Health Service Standards* 

Second edition [Online]. Available from

https://www.safetyandquality.gov.au/sites/default/files/migrated/National-Safety-and-Quality-Health-Service-Standards-second-edition.pdf

19. NICE *Patient experience in adult mental health: improving the experience of care for people using adult NHS mental health services* [Online]. Available from https://www.nice.org.uk/guidance/cg136.

20. Department of Health and Aged Care Australian Government *National Standards for Mental Health Services 2010 and implementation guidelines* [Online]. Available from <u>https://www.health.gov.au/resources/publications/national-standards-for-mental-health-</u> <u>services-2010-and-implementation-guidelines?language=en</u>.

21. Department of Health and Aged Care Australian Government *Primary Health Networks (PHNs)* [Online]. Available from <u>https://www.health.gov.au/our-work/phn?utm\_source=health.gov.au&utm\_medium=callout-auto-custom&utm\_campaign=digital\_transformation</u>.

22. Department of Health Australian Government. *Primary Health Networks Grant Programme Guidelines.* 2016. Available from:

https://www.health.gov.au/sites/default/files/documents/2021/04/primary-health-networks-phn-grant-program-guidelines.pdf.

23. Department of Health and Aged Care Australian Government *Primary Health Networks (PHN) collection of primary mental health care resources* [Online]. Available from <a href="https://www.health.gov.au/resources/collections/primary-health-networks-phn-collection-of-primary-mental-health-care-resources">https://www.health.gov.au/resources/collections/primary-health-networks-phn-collection-of-primary-mental-health-care-resources</a>.

24. *Head to Health* [Online]. Available from <u>https://www.headtohealth.gov.au/</u>.

25. *Initial Assessment and Referral Decision Support Tool (IAR-DST)* [Online]. Available from <a href="https://nwmphn.org.au/our-work/mental-health/initial-assessment-and-referral-decision-support-tool/">https://nwmphn.org.au/our-work/mental-health/initial-assessment-and-referral-decision-support-tool/</a>.



26. Department of Health Australian Government *Australian Government's Primary Mental Health Care Minimum Data Set (PMHC MDS)* [Online]. Available from <u>https://pmhc-mds.com/</u>.

27. AMHOCN *Your Experience of Services Primary Health Networks survey* [Online]. Available from <u>https://www.amhocn.org/training-and-service-development/experience-measures/application-for-use</u>.

28. AMHOCN *Australian Mental Health Outcomes and Classification Network* [Online]. Available from <u>https://www.amhocn.org/</u>.

29. Department of Health Australian Government. *Guide for licensed PHNs and PHN commissioned service providers seeking a license to use the instrument*. 2020. Available from:

https://www.amhocn.org/ data/assets/pdf file/0018/700452/yes phn guidance v1.0 202 00408.pdf.

30. *Primary Mental Health Care Minimum Data Set (PMHC-MDS)* [Online]. Available from <u>https://pmhc-mds.com/</u>.

31. NHMRC *National Health and Medical Research Council* [Online]. Available from <u>https://www.nhmrc.gov.au/research-policy</u>.

32. The Danish Health Data Agency *Danish National Patient Registry* [Online]. Available from

https://sundhedsdatastyrelsen.dk/da/english/health\_data\_and\_registers/healthdatadenmark/dataauthorities.

33. Defactum.dk [Online]. Available from

https://www.defactum.dk/kvalitetsudvikling/sporgeskemaundersogelser/lup-psykiatri.

34. *LUP Psychiatry Summary 2021* [Online]. Available from

https://www.defactum.dk/siteassets/sider/kvalitetsudvikling/lup-

psykiatri/2021/rapporter/lup-psykiatri\_national-one\_pager-2021.pdf.

35. LUP Psychiatry 2023 [Online]. Available from

https://www.defactum.dk/siteassets/sider/kvalitetsudvikling/luppsykiatri/2023/psykiatri onepager 2023 samlet.pdf.

36. A. Bjertnaes Ø, A. Garratt, J. O. Johannessen. [Data collection methods and results in patient surveys in mental health care]. *Tidsskr Nor Laegeforen*. 2006; 126(11):[1481-3 pp.].

37. A. Garratt, K. Danielsen, A. Bjertnaes Ø, T. Ruud. [PIPEQ--a method for measurement of user satisfaction in mental health services]. *Tidsskr Nor Laegeforen*. 2006; 126(11):[1478-80 pp.].

38. O. Bjertnaes, H. H. Iversen, J. Kjollesdal. PIPEQ-OS--an instrument for on-site measurements of the experiences of inpatient users at psychiatric institutions. *BMC Psychiatry*. 2015; 15:[234 p.].

39. Hilde Hestad Iversen, Mona Haugum, Oyvind Bjertnaes. Reliability and validity of the Psychiatric Inpatient Patient experience Questionnaire – Continuous Electronic Measurement (PIPEQ-CEM). *BMC Health Services Research*. 2022; 22(1):[897 p.]. Available from: https://doi.org/10.1186/s12913-022-08307-5.

40. Hilde Hestad Iversen, Mona Haugum, Oyvind Bjertnaes. Additional file 1 of Reliability and validity of the Psychiatric Inpatient Patient Experience Questionnaire – Continuous Electronic Measurement (PIPEQ-CEM) 2022. Available from:

https://springernature.figshare.com/articles/journal\_contribution/Additional\_file\_1\_of\_Reliabi lity\_and\_validity\_of\_the\_Psychiatric\_Inpatient



user\_Patient\_Experience\_Questionnaire\_Continuous\_Electronic\_Measurement\_PIPEQ-CEM\_/20296420.

41. Statista *United Kingdom - Statistics & Facts* [Online]. Available from <u>https://www.statista.com/topics/755/uk/#topicOverview</u>.

42. NHS *The NHS Long Term Plan* [Online]. Available from

https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf.

43. England.nhs.uk *The Five Year Forward View For Mental Health* [Online]. Available from <a href="https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf">https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf</a>.

44. NHS England *The community mental health framework for adults and older adults* [Online]. Available from <a href="https://www.england.nhs.uk/publication/the-community-mental-health-framework-for-adults-and-older-adults/">https://www.england.nhs.uk/publication/the-community-mental-health-framework-for-adults-and-older-adults/</a>.

45. Department of Health and Social Care *NHS Constitution for England (Updated in 2015)* [Online]. Available from <u>https://www.gov.uk/government/publications/the-nhs-constitution-for-england</u>.

46. Department of Health and Social Care *Health and Social Care Act 2012: fact sheets* [Online]. Available from <u>https://www.gov.uk/government/publications/health-and-social-care-act-2012-fact-sheets</u>.

47. Care Quality Commission *New CQC strategy champions regulation driven by people's experiences of care* [Online]. Available from <u>https://www.cqc.org.uk/news/releases/new-cqc-strategy-champions-regulation-driven-peoples-experiences-care</u>.

48. Care Quality Commission *Privacy Statement* [Online]. Available from <u>https://www.cqc.org.uk/about-us/our-policies/privacy-statement</u>. Accessed on:

49. Legislation.gov.uk *Section 251 of the National Health Service Act 2006* [Online]. Available from <u>https://www.legislation.gov.uk/ukpga/2006/41/section/251</u>.

50. Care Quality Commision. *Information Governance Policies.* 2024.

51. NHS Surveys. *Community Mental Health Survey Sample Declaration Form* 

52. *NHS Approval to undertake research* [Online]. Available from

https://www.hra.nhs.uk/planning-and-improving-research/research-planning/.

53. Care Quality Commission *Community Mental Health Survey 2023 Benchmark Reports* [Online]. Available from <u>https://nhssurveys.org/all-files/05-community-mental-health/05-benchmarks-reports/2023/</u>.









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