

# Keyworking Programme: National Evaluation

## Purposes for processing

### Background

NHS England & NHS Improvement (NHSE/I) have developed the Keyworking Programme in response to the NHS Long Term Plan (LTP) commitment that by 2023/24, autistic children and young people (CYP) and CYP with a learning disability, with the most complex needs, will have a designated Keyworker, implementing the recommendations made by Dame Christine Lenahan. Initially, Keyworking support will be provided to autistic CYP and CYP with learning disability, who are inpatients or at risk of being admitted to hospital, but it is envisaged that support will also be extended to those who face multiple vulnerabilities such as looked after and adopted children, and CYP in transition between services.

The national evaluation has been commissioned to understand the impact of different iterations of a core Keyworking model across varying geographies, to inform funding decisions and refine and develop plans for future rollout.

NHSE/I have commissioned **NHS Arden & GEM Commissioning Support Unit** who are working with the **National Children's Bureau** to undertake the national evaluation of the Keyworking programme, working with the sites selected by NHSE/I to participate in the second wave rollout (early adopter areas) of the programme. The participating sites are detailed in Appendix 1.

Autistic CYP and CYP with a Learning Disability requiring the Keyworking Programme within the participating sites will be part of the evaluation of the required delivery of service to this specific cohort of patients, as per the NHSE/I Long Term Plan in support of addressing service provision to specific service user groups.

Following the Keyworking evaluation, which will be carried out with the input of the participating **sites** which includes multi-organisational staff, service user, service user family & carers, volunteers, all relevant multi-organisation records & documents, interviews, focus groups and questionnaire outcomes, the evaluator will report their findings to the NHSE/I commissioner. This will help to determine the picture of progress of the Keyworking Programme in line with the NHS Long Term Plan and will support with the management and planning of future developments of the Keyworking Programme.

NHSE/I is conducting this national evaluation to understand the impacts and value of the programme. The evaluation is expected to demonstrate impacts on patient health-related outcomes and experience, impact on parents/ carers and the system and quality of service for CYP and wider health inequalities. Findings from the evaluation will ensure an evidence-based approach to NHSE/I's longer-term strategy for wider roll out of the Keyworking programme of work.

## Fair Processing Notice Template – Keyworking Programme National Evaluation data process requirements

This approach involves the analysis of data collected by the programme, and information recorded in interviews with patients, family, carers, and multi-organisational staff about their experiences.

**NHS Arden & GEM Commissioning Support Unit** and the **National Children's Bureau** has been appointed as NHSE/I's national evaluation partner. No person identifiable data will be shared with the NHS England commissioner of this programme, only anonymised information for purpose of reporting the recorded aims and objectives will be shared with NHS England commissioner.

## Sources of data and categories of personal data

All local area (**site**) multi-organisational service records and documents, staff, family, carers, and relevant volunteers who are acting on behalf of the service user to achieve the Keyworking Framework objectives. **NHS Arden & GEM Commissioning Support Unit** and **National Children's Bureau** will make contact with all sites for access to relevant information for successful evaluation, and additional arrangements for interview, focus groups and/or completion of questionnaires (outcome measure).

Personal data, and Personal Confidential data about patients/service user is collected across the pathway of sites for the provision of the service locally. **NHS Arden & GEM Commissioning Support Unit** and **National Children's Bureau** will receive records and documents from these local service contributors for the purpose of evaluation. Participants will be identifiable to the evaluator from this data flow. The dataset will include information on sex, age, information about diagnosis, treatment, and outcomes (please see detail contained within table).

**NHS Arden & GEM Commissioning Support Unit** and **National Children's Bureau** will also collect information about the experiences of the participants and multi-organisational staff, family, and carers facilitated by the participating sites. Information will be recorded in an identifiable format by first gaining explicit consent from the individual to conduct interviews, focus groups and questionnaire completion; participants of this specific process can at any point ask for their interview, feedback and/or survey contribution to be removed from the evaluation report.

## Categories of recipients

**NHS Arden & GEM Commissioning Support Unit** and **National Children's Bureau** will receive patient/service user, staff identifiable data, along with, where possible and practical to the required outcomes of this process, pseudonymised data. **NHS Arden & GEM Commissioning Support Unit** and **National Children's Bureau** will also collect information through interviews, which will be anonymised before sharing with NHS England. **NHS Arden & GEM Commissioning Support Unit** and **National Children's Bureau** will act as, under contract, a processor for NHS England for the purposes of the National Keyworking Function evaluation programme of work.

## Legal basis for processing

For GDPR purposes NHS England’s lawful basis for processing is Article 6(1)(e) – ‘...exercise of official authority...’;

For the processing of special categories (health) data the basis is 9(2)(h) – ‘...health or social care...’, and 9(2)(j) ‘...statistical purposes...’.

<b>Area of work</b>	<b><i>National Evaluation of the Keyworking Programme for autistic children and young people (CYP) and CYP with learning disabilities</i></b>
<b>Processed on behalf of</b>	NHS England
<b>Purpose/s for Processing</b>	<p>National Evaluation of Keyworking programme:</p> <p style="padding-left: 40px;">Information processed in relation to people with a learning disability, autism spectrum disorder or both who are subject to keyworking in line with the Evaluation Framework</p> <p>The process will include obtaining health and social care information from relevant providers including Hospital Records, District Nursing Team Records, Community Mental Health Team Records, GP Records, Social Care Records, Nursing / Residential Home Record, Voluntary Sector Providers, and assessments.</p> <p>Assessment format of NHS, Social Care, Voluntary Community &amp; Social Enterprise, Local Authority staff carrying out the Keyworking Function. Interviews, focus groups, completion of questionnaires (National Outcome measures).</p> <p>To gather information that will contain Personal and Special Category Data; to assess whether the national outcomes of the keyworking function set out in the framework are being met and maintained. Only Aggregated/Anonymised data on performance of the Keyworking Function will be shared with the Commissioning Board (NHSE/I)</p>
<b>Format used</b>	Electronic Paper

## Fair Processing Notice Template – Keyworking Programme National Evaluation data process requirements

<b>Area of work</b>	<b><i>National Evaluation of the Keyworking Programme for autistic children and young people (CYP) and CYP with learning disabilities</i></b>
<b>Legitimate Interests</b>	<i>N/A for Public Sector</i>
<b>Personal Data processed:</b> <i>Items that can be used to identify an individual to include a Pseudonymisation code/key (this list is not exhaustive)</i> Name DOB Address Location Data NHS Number	Name Date of Birth Date of Death Address Postal code Location data NHS Number Telephone Number Email Address
<b>'Special Category' Data Processed:</b> (all items that fall under DP law listed) Race Ethnic origin Politics Religion Trade Union membership Genetics Biometrics (when used for ID purpose) Health Sex life; or Sexual orientation	Age Disability Health Race Ethnic Origin Religion or belief Sex Gender reassignment Sexual orientation
<b>Transfer of Data outside the UK</b>	Yes; Ad-hoc correspondence to persons who live outside the UK
<b>Transfer of Data outside the EU</b>	Yes; Ad-hoc correspondence to persons who live outside the UK
<b>Retention Period Criteria used:</b>	NHS Records Management Code of Practice 2021 Category of record applied: Patient record
<b>The source the personal data originates from</b> and whether it came from publicly accessible sources	GP Practice NHS Digital Integrated Care Board/Integrated Care System/ Clinical Commissioning Group Acute Mental Health Trust

Fair Processing Notice Template – Keyworking Programme National Evaluation data process requirements

<p><b>Area of work</b></p>	<p><b><i>National Evaluation of the Keyworking Programme for autistic children and young people (CYP) and CYP with learning disabilities</i></b></p>
	<p>Voluntary Community and Social Enterprise                  Community Trust Providers                  Patient                  Member of public etc.                  Family and other representatives of the patient                  Local Authorities                  Legal representatives</p>
<p><b>Whether the provision of personal data is part of a statutory or contractual requirement or obligation and possible consequences of failing to provide the personal data</b></p>	<ul style="list-style-type: none"> <li>• Contractual</li> <li>• Statutory                         <ul style="list-style-type: none"> <li>Article 6 (1) (e) ‘.... exercise of official authority...’ Public Task</li> <li>Article 9 (2) (h) ‘.....health &amp; social care.....’</li> <li>Article 9 (2) (j) ‘.....statistical purposes...’</li> </ul> </li> <li>• Introduction to carry out interview only - Explicit Consent from NHS, Social Care, VCSE, LA staff, CYP, Family members, and/or carers to conduct evaluation interviews, focus groups.</li> </ul>
<p><b>The existence of automated decision making,</b> (making a decision solely by automated means without any human involvement); including profiling and information about how decisions are made, the significance and the consequences.</p>	<p>n/a</p>

**Appendix 1. Early adopter areas**

## Fair Processing Notice Template – Keyworking Programme National Evaluation data process requirements

- Birmingham and Solihull
- Bristol, North Somerset and South Gloucestershire
- Buckinghamshire
- Cambridge and Peterborough
- Cheshire and Mersey
- Gloucestershire
- Hampshire and Isle of White
- Humber Coast and Vale
- Kent and Medway
- Leicester, Leicestershire and Rutland
- Norfolk and Waveney
- North Cumbria and the North East
- South East London
- Staffordshire and Stoke on Trent

Source: [NHS England » Children and young people keyworkers](#). Accessed: 25/7/2022