

# Making a difference for children, young people and families' lives in the North East

Recommendations for the next steps  
In using routinely collected data



**Final report**  
**The Child Routine Data: North East Task-and-Finish Group**  
**April 2021**

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# 1. EXECUTIVE SUMMARY

## PURPOSE

A Child Data Group was convened in the Autumn 2020 as the first step to producing an overview of childhood routine data capacity in the North East. The group was set up in a short-term, task and finish format, to meet for five times to discuss a range of objectives, and finally to make clear recommendations for the next steps in terms of improving access, linkage and processing capabilities for child routine data. The group's work was designed to form the basis for a further action plan for routine child data use at scale.

The areas for the group to discuss were:

- i. The main existing sources of child routine data in the North East, and the nature of these data.
- ii. Current access levels and processes to these different types of data.
- iii. Technical feasibility of linking these data to inform clinical, service and scientific questions.
- iv. The key challenges across i-iii.

Underpinning the Group's work was a desire to develop national leadership in child routine data to advance innovation, research, and care, and inform policy and commissioning.

## METHOD

The Group used a collaborative, approach where all contributions were valued equally, and all stakeholders were supported to have a voice. The Chair generated the initial agenda for the first meeting based on the objectives, above. At that, the agenda for the subsequent three meetings were jointly generated and agreed. That agenda consisted of three key questions:

- Why use and link data – what tangible benefits will children, young people and families expect to see as the result of it?
- What data is, and should be, of concern here?
- What are the technical, ethical and moral issues?

The group consisted of 28 members, representing families and young people, the local authority, various parts of the NHS, social care, education, and academia.

The Group's five meetings were all via Zoom, and lasted an hour. Follow up work, to support the group's progress, were undertaken in between meetings.

## MAIN THEMES

### Better health and well-being for children and families

Starting point for any data use must be the tangible difference we expect to make for children, young people and families' lives. Using routinely collected, summarised information about children, young people and families would:

- Support communities and decision makers to understand the health and wellbeing of children and young people, enabling advocacy for children, young people and families.
- Provide a platform for service improvement across the health, education, social-care, and justice sectors; and for preventing problems early before they emerge.
- Enable exploration and development of new solutions and ideas for public good.

The related infrastructure would further provide opportunities for training and employment for the young people in the region.

### The content of routine information

Using routinely collected information (*data*) about the health and well-being of children, young people and families—collated and summarised (*aggregated*) so that no individuals can be identified—to improve services, supports, places and structures involves two key considerations:

- It is essential to select the right information that allows making a meaningful difference. For this, what is right information, and what are the most meaningful indicators of health and well-being for children, young people and families, needs to be defined.
- Existing routinely collected information provides a potentially valuable starting point. Making these data discoverable is essential.

### Practical opportunities requiring timely action

Major regional and national infrastructure projects are under way to progress secure data sharing and linkage. The current regional work largely uses adult populations as the starting point, and there are important opportunities for the Great North Children's Research Community to bring childhood and youth perspective into these. Nationally, and in the other regions, work is happening in childhood and youth place – if we do not take action now we run the risk of missing out on important funding opportunities and being behind, ultimately the children, young people and families in the region missing out.

## CONCLUSIONS

The Group's work has brought together key expertise across the North East, and provides a clear starting point for planning next steps in a way that has support across sectors. The Group makes six recommendations related to the main themes.

## 2. RECOMMENDATIONS

1. To develop examples that clearly demonstrate the power of data for improving health and well-being indicators that really matter to children and young people; and what good governance looks like from the children, young people and families' perspective. There are several national initiatives with linked funding (e.g. by ESRC, NIHR) that could be accessed.
2. Work with children, young people and families to identify key indicators of health and well-being for the next 10-15 years. Advancing this work aligns with the NIHR ARC Families Theme priorities, and the Theme has agreed provisionally to support this. YPAG North East is also supportive of joint work.
3. Begin to scope what routine data exist, and present it in a data dictionary that could, if appropriate, subsequently inform the Great North Care Record data dictionary. We have secured initial seed-funding (NUTH RCF CHIMES) to support this work.
4. Scope with key organisations across health, education, social-care, and justice to identify national data returns that they are expected to do but currently find challenging to effectively deliver due to a lack of data; and explore these as opportunities for new indicators.
5. The Great North Children's Research Community is well placed to provide leadership in ensuring young people and families are strongly involved in governing children and young people's information. A specific plan for how best to achieve this is needed.
6. To inform strategic plans for building childhood and youth data capacity and capability and an analysis of strengths, opportunities and gaps is needed.

In addition – if the recommendations endorsed and action groups to continue, recommended that these would jointly report to the Steering Group from three to four times a year with a robust and two-way discussion at those time points.

### 3. MAIN THEMES: ELABORATED DESCRIPTION

#### Better health and well-being for children and families

The starting point must be the tangible difference we expect to make for children, young people and families' lives. Using routinely collected, summarised information about children, young people and families can advance that in four ways.

**The information would support communities and decision makers to understand the health and wellbeing of children and young people, and enables advocacy for children, young people and families.** For example, the information can be used to highlighting important health and well-being inequalities, and steer investment. It can be used to influence policy makers, service leaders and commissioners to focus on aspects of health and well-being matter to children and families.

**The information would provide a platform for service improvement by closely monitoring impacts of services across the health, education, social-care, and justice sectors.** For example, if we had access to meaningful information about overall health and well-being of children and young people in the North East, we could shape services, supports and environments so that they work best for children, young people and families' priorities – and so that they have meaningful, fair benefits for all. We could better connect services across sectors rather than working in silos. We could enable services to monitoring changes over time, respond to changing contexts, and act in a data-informed way.

We could identify and prevent problems early before they even exist, or before they get too complex – and we could do this at scale. For example, combining information from different sources would allow communities and services to detect early signals, and give communities control over their own health and well-being. It would help targeting resources and tailoring supports. It could lead to identification of new early warning signals and new early supports.

**The information would enable exploration and development of new solutions and ideas for public good.** For example, investigating patterns in the information and comparing them across areas and communities could help to discover new ideas that we do not yet even know about. Flagging gaps in health and well-being would guide decisions about topics where new innovations need to be developed. The information would help better considerations ('modelling') of what impact different interventions might have before they are even developed. It would provide feedback about emerging health, care and education innovations, and allow them to be tested for benefits and harms against indicators that matter to children, young people and families.

**The wider infrastructure related to collecting, collating and sharing the information would also provide opportunities for training and employment for the young people in the region.** Building the data capacity and infrastructure in the North East provides new avenues of development and employment for the next generation of children and young people. Investing in information and data infrastructure is investing in the future.

#### RECOMMENDATION:

1. To develop examples that clearly demonstrate the power of data for improving health and well-being indicators that really matter to children and young people; and what good governance looks like from the children, young people and families' perspective. There are several national initiatives with linked funding (e.g. by ESRC, NIHR) that could be accessed.

## The content of routine information

Using routinely collected information (*data*) about the health and well-being of children, young people and families to improve services, supports, places and structures involves a number of considerations.

For the present report, we have understood health and well-being broadly, involving different public services (health, education, social work, social justice, other local authority). Our focus has been on existing and potential future information ('data') that is routinely collected as part of the day-to-day activity by the public services. We have focuses on collated and summarised (*aggregated*) information where no individuals can be identified. Within these boundaries, we have identified two key considerations that require imminent attention.

**It is essential to select the right information that allows making a meaningful difference.**

**However, what is right information is not yet defined.** The key question for moving forward is, what are the most meaningful indicators of health and well-being for children, young people and families in the North East in the next 10-15 years. Answering this was beyond the work of the present group but doing so is felt to be an essential next step to inform what existing routine data to use and what new routine indicators might be needed. Undertaking such work would seem to fit well with the prioritise of the NIHR ARC Families Theme, as well as the strategic role of the YPAG North East.

**Existing routinely collected information provides a potentially valuable and cost-effective starting point. Understanding what these data are, and making them discoverable, is essential.** It is clear that much data already exists across the health, education, social-care, and justice sectors. However, where these information are, how true and accurate they are, and how they can be accessed are largely unknown. There is related discussion under the Great North Care Record umbrella, to progress a regional data dictionary that would enhance discoverability of data. However, it is not yet clear what the plans for this may be and whether children, young people and family's data are included. The group had some key expertise that would allow some of the mapping to progress, if appropriate resources could be secured.

### RECOMMENDATIONS:

2. Work with children, young people and families to identify key indicators of health and well-being for the next 10-15 years. Advancing this work aligns with the NIHR ARC Families Theme priorities, and the Theme has agreed provisionally to support this. YPAG North East is also supportive of joint work.
3. Begin to scope what routine data exist, and present it in a data dictionary that could, if appropriate, subsequently inform the Great North Care Record data dictionary. We have secured initial seed-funding (NUTH RCF CHIMES) to support this work.
4. Scope with key organisations across health, education, social-care, and justice to identify national data returns that they are expected to do but currently find challenging to effectively deliver due to a lack of data; and explore these as opportunities for new indicators.

## Practical opportunities requiring timely action

In addition to what information to use and why, key issues relate to how the data is accessed and brought together. Meaningful information that provides an accurate representation of a chosen health or wellbeing indicator is likely to exist across datasets which do not currently speak to one another (i.e. which are not linked).

Ideally, there would be a secure, accessible way that makes finding relevant information easy, such as a “data dashboard” to inform improvement and innovation.

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*We would have a data dashboard to help to connect the dots and design right supports that happen at the right time in the right place for the right people. To connect the information up across boundaries.*

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While a dashboard is an unlikely reality soon, major regional and national infrastructure projects are under way to explore ways for secure data sharing and linkage. These largely use adult populations as starting point, and there are important opportunities for the Great North Children’s Research Community to bring childhood and youth perspective into these.

**Ensuring that children, young people and families’ voices are heard in data sharing systems, infrastructure and governance processes is imperative.** We have identified regional opportunities where the Great North Children’s Research Community could lead this; and best practice examples from other regions and nationally that could inform the work in the North East.

**Making appropriate and effective use of the emerging data opportunities requires human capacity and capability.** Childhood and youth data capacity in the North East is spread across organisations and networks. There are open questions about what the digital skills and capacity within the Community are, and what further capacity may be needed. Clarity on these would facilitate strategic planning and related business cases.

### RECOMMENDATIONS:

5. The Great North Children’s Research Community is well placed to provide leadership in ensuring young people and families are strongly involved in governing children and young people’s information. A specific plan for how best to achieve this is needed.
6. To inform strategic plans for building childhood and youth data capacity and capability, an analysis of strengths, opportunities and gaps is needed.



## 4.APPENDICES

### APPENDIX A: Examples of questions that using routine data would help to answer

Table A1. Examples of questions related to improving services and supports for children and young people

<b>Questions asked</b>
<ul style="list-style-type: none"><li>• Are children and young people across the North East flourishing?</li><li>• How healthy and well are the children and young people in the North East?</li><li>• Are there particular groups or communities that are less healthy or well than others – or that are at particular risk of poor health, education and wellbeing?</li><li>• Are there early warning signals that some (groups of) children or young people are becoming unwell, or that their health or well-being is beginning to fall behind?</li><li>• Are there particular communities or areas we should focus on for support?</li><li>• Are there particular communities and groups that are doing especially well – what can we learn from them?</li><li>• What factors make children and young people's health and well-being better or worse?</li><li>• Are our services, supports and interventions making a difference?</li><li>• How can we mitigate risks and support children to flourish?</li><li>• How should we change or improve services to make a difference?</li><li>• How can we make our services responsive to changing needs in communities?</li><li>• Are there particular issues or communities where we should work across organisational and professional boundaries?</li></ul>

Table A2. Examples of questions related to developing innovations for children and young people

<ul style="list-style-type: none"><li>• What are the trends and clusters of health and well-being among children and young people in the North East – and what seems to be driving these?</li><li>• What health and well-being impact should new innovations seek to achieve?</li><li>• What is the minimum information that I need in order to decide whether an innovation brings more benefits than harm?</li><li>• Is a new innovation helping to improve the quality of services in a meaningful way?</li><li>• What early signals can warn the system about health and well-being problems?</li><li>• How can these problems be prevented?</li><li>• What entirely new questions is this data suggesting we ask?</li><li>• Moving towards a system where e.g a clinician or practitioner can implement a new intervention and then use routinely collected data to understand change and improvement</li></ul>
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## APPENDIX B: Examples of what information could be used

Table B1. Potential indicators of health and well-being emerging from the discussion

Mental health
Healthy food
Healthy weight
Learning, education
Developing independence in caring for oneself
School attendance as a marker of disadvantage
participation
maternity/breastfeeding
childhood deprivation
safeguarding and abuse
disability
chronic disease
pollution
maternal bonding
diet
immunity
infection
allergy
family education
changing patterns due to the pandemic – e.g. RCPCH had recently highlighted a 4x increase in eating disorders during lockdown

## APPENDIX C: Steering Group members

Name	Organisation
Alexandra Battersby	The Newcastle Upon Tyne Hospital NHS Foundation Trust
Allan Fairlamb	Cumbria, Northumberland, Tyne & Wear NHS Foundation Trust
Allison Farnworth	Newcastle University
Bateman Belinda	Northumbria Healthcare NHS Foundation Trust
Chris Drinkwater	Ways to Wellness
Chris Emmerson	Newcastle University
Christine Pearson (Administrator)	Newcastle University
Christopher Wilcockson	Northumbria Healthcare NHS Foundation Trust
Cristina McKean	Newcastle University
Dean McNally	Action for Children (Parent Volunteer)
Helen Wareham	Newcastle University
Ian Robson	Northumbria University
James Law	Newcastle University
Joanne Ball	The Newcastle Upon Tyne Hospital NHS Foundation Trust (Young Persons Advisory Group North East)
Judith Rankin	Newcastle University
Kianoush Nazarpour	Edinburgh University
Lindsay Little	Action for Children (Parent Volunteer)
Louise Michaelis	Newcastle University & The Newcastle Upon Tyne Hospital NHS Foundation Trust
Matthew Forshaw	Newcastle University
Michael Taggart	Newcastle University
Niina Kolehmainen (Chair)	Newcastle University
Ruth McGovern	Newcastle University
Stephen Foreman	Newcastle City Council
Stuart Wheeler	Newcastle University
Sue Thompson (Administrator)	Newcastle University
Sunil Bhopal	Newcastle University
Toby Quibell	North East Wellbeing
Victoria Harbottle	The Newcastle Upon Tyne Hospital NHS Foundation Trust
Vikki Smith	NIHR Advocate (Midwifery)