

# Data and Standards Task and Finish Group Report

## Children and Young People's Mental Health and Wellbeing Taskforce

This report summarises proposals from the 'Data and Standards' Task and Finish Group of the Children and Young People's Mental Health and Wellbeing Taskforce and has informed the report *Future in Mind: promoting, protecting and improving our children and young people's mental health and wellbeing*. **It is not a statement of Government policy.** A full list of members and contributors is included at the end of the report.

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# Introduction

1. The Data and Standards Task and Finish Group brings together a wide range of expertise and experience from across the health, social care, youth justice, education, voluntary sector and independent provider systems. Discussions in the group have prioritised the following key areas for action:
  - common service standards;
  - gaps in child mental health data – particularly in relation to funding flows;
  - outcomes measures;
  - performance data and payment systems;
  - access and waiting times;
  - giving children and young people and those who care for them more control over their health and wellbeing (eg through better use of digital tools).

## The vision

2. Services need to be outcomes-focused, holistic, accessible, built around the needs of children, young people and their families and informed by their views. They should be based on best evidence and not defined in terms of organisational boundaries.
3. The vision is for a child mental health infrastructure that underpins this shared set of principles, with data and payment systems, outcome measures, service standards and regulatory frameworks that align across the whole system - NHS, Public Health, social care, youth justice, and education - to deliver improvements in child mental health outcomes.
4. There is widespread stakeholder support for the Children and Young People's Improving Access to Psychological Therapies (CYP IAPT) programme that has underpinned transformation of child and adolescent mental health services with £60 million funding invested in service improvement and training.

## The key challenges

5. Good data and information on mental health services are crucial to enabling policy makers, providers, commissioners and the public to understand how the system and organisations are performing and to support decision making.
6. However, the Chief Medical Officer's Annual Report 2013<sup>1</sup> highlights a lack of nationally collated data on the present extent of children and young people's mental health problems and service provision. The challenges are well documented and include:

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<sup>1</sup> Annual Report of the Chief Medical Officer 2013, Public Mental Health Priorities: Investing in the Evidence

- a lack of national, standardised information on the present extent of all aspects of child and adolescent mental health services (CAMHS) use, spend and outcomes;
- a lack of adequate IT infrastructure in providers for primary and secondary data collection and use;
- the major challenge of improving data linkage across sectors;
- a lack of a national process or oversight of the development of primary datasets;
- service providers being subject to increasing, and sometimes contradictory, demands for multiple data entry.

## Summary of key proposals

- An agreed set of core service standards building on existing evidence-based approaches to service accreditation and quality assurance should align with, and be reinforced by, CQC's five Essential Standards (Safe, Effective, Caring, Responsive, Well-led) and accompanying key lines of enquiry.
- CQC and Ofsted - with their distinct roles and responsibilities in health and education - should develop a joint cross inspectorate view of how the health, education and social care systems are working together to improve children and young people's mental health outcomes and how this area should be monitored in future.
- The Department of Health should commission a regular prevalence survey of child and adolescent mental health every 5 years, giving particular consideration to including those aged under 5 and over 15.
- NHS England are improving their spending data from April 2015 so that it will be able to identify the overall spend in primary and community care as well as mental health services and specialist commissioning. This has been built into the NHS planning process at CCG level. This activity should be extended to cover children's mental health spend by the NHS.
- Further work should be done to improve understanding of child and adolescent mental health funding flows across health, education, social care and youth justice to support a transparent, coherent whole system approach to future funding decisions and investment.
- Routine data collection of key indicators of child and adolescent mental health service activity, patient experience and patient outcomes should be co-ordinated and incentivised.
- The NHS and Public Health Outcomes Frameworks should work together to develop a metric that recognises children and young people's experience of their mental health care and incentivises effective integration of care to meet their needs.
- Future development of financial incentive systems across health, education and children's social care are aligned to drive improvements in children's mental health outcomes.
- In developing access standards for CAMHS, access to services should be reported as the time to different events within a pathway, and linked to outcomes at each step.

- NHS Choices content on mental health should reference/make links to the children and young people equivalent – the Youth Wellbeing Directory.
- Children’s mental health services should be included in the digital maturity assessment work being taken forward by NHS England.
- Children and Young People’s Mental Health should be included in the work programme outlined by the National Information Board’s Framework for Action.
- The Taskforce should agree a shared definition of key terms and how these should be interpreted in different sectors.

## Health Select Committee Inquiry into Children's and Adolescents' Mental Health and CAMHS

7. Key recommendations from the Committee’s Report<sup>2</sup> for the work of the Data and Standards Task and Finish Group include the following:

### **HSC Recommendation 2**

*The Committee is deeply concerned that the most recent ONS data on children’s and young people’s mental health is now ten years old, as up-to-date information is essential for the safe and effective planning of health services. We welcome the Government’s commitment, made during the course of this inquiry, to fund a repeat of the ONS prevalence survey. It is essential that this survey is not a one-off, but is repeated on an ongoing basis. We recommend that the Department of Health/ NHS England taskforce adds the issue of the quality of ongoing data to its terms of reference. (Paragraph 23)*

### **HSC Recommendation 3**

*Not only is there a lack of data on children and young people’s mental health, but also a worrying lack of comprehensive and reliable information about children’s and adolescents’ mental health services, including referrals, access and expenditure. In the words of the Minister, CAMHS services have been operating in a “fog”, and efforts to improve data availability have been subject to delays. This is unacceptable. Ensuring that commissioners, providers and policy-makers have access to up-to-date information about all parts of CAMHS services – from early intervention up to inpatient services – is essential. We recommend that this is a priority for the Department of Health/ NHS England taskforce. (Paragraph 24)*

### **HSC Recommendation 25**

*It is clear that there are currently insufficient levers in place at a national level to drive essential improvements to CAMHS services. These have received insufficient scrutiny from CQC and we look to review progress in this area following their new inspection regime. The Minister has argued that waiting time targets will improve CAMHS services but we recommend a broader approach that also focuses on improving outcomes for specific conditions in children’s and adolescents’ mental health. (Paragraph 249)*

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<sup>2</sup> Health Committee Child and Adolescent Mental Health and CAMHS – 3<sup>rd</sup> report of session 2014/15

# An agreed set of common service standards

8. Innovation across sectors underlines the importance of standardisation of processes to support and drive quality improvement.
9. The group agreed that a shared set of core principles should underpin a common set of best practice service standards that apply across the whole system.
10. These should align with the established quality frameworks that have incorporated the principles of CYP IAPT and underpin the CAMHS service transformation programme underway covering 54% of the 0 – 19 population of England (rising to 68% during 2015).
11. The standards should build on existing evidence-based approaches to service accreditation and quality assurance rather than invent new ones adding further burdens for frontline agencies.
12. Work to develop a common set of standards is in progress. The *Delivering With and Delivering Well*<sup>3</sup> guidance document identifies key markers underpinning the values and qualities of the programme. These include:
  - access and referral criteria and processes
  - advocacy and support
  - transition
  - information
  - routine outcome measurement
  - leadership
  - workforce – capacity and competence
  - demand and capacity management
13. These markers are recognised in the existing quality assurance and quality process mechanisms: the Quality Network for Community CAMHS (QNCC), the Youth Wellbeing Directory with ACE-V Quality Standards (ACE-V), the Choice and Partnership Approach (CAPA) and the Child Outcomes Research Consortium (CORC).
14. The same standards should also be built into standard contracts for services, linked to payment, reporting and performance management systems so that there is transparency about performance data. This should include the outcomes from interventions and what CYP and their families say, so that professionals can see how they are performing and CYP can make informed choices, and to help commissioners commission the best care.
15. **This Task and Finish group proposes that these core service standards building on existing evidence-based approaches to service accreditation and quality assurance should align with, and be reinforced by, CQC's five Essential Standards (Safe, Effective, Caring, Responsive, Well-led) and accompanying key lines of enquiry.**

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<sup>3</sup> CAMHS : Service Values and Standards : Delivering With and Delivering Well () <http://www.england.nhs.uk/wp-content/uploads/2014/12/delvr-with-delvrng-well.pdf>

16. Further action is needed to ensure a coherent overarching regulatory framework for CAMHS. **This Task and Finish group proposes that CQC and Ofsted - with their distinct roles and responsibilities in health and education - should develop a joint cross inspectorate view of how the health, education and social care systems are working together to improve children and young people’s mental health outcomes and how this area should be monitored in future.**

## Gaps in child mental health data

*“How can services be commissioned appropriately if we don’t know what demand really is?”*

*A youth justice employee who took part in the Taskforce engagement exercises*

17. Good health support and services should be based on high quality, accurate data. There are currently significant gaps in relation to children’s mental health data right across the spectrum, including on prevalence, mental health promotion, prevention and risk reduction as well as on service level data and spend.
18. A number of developments are underway. Implementation of the CAMHS Minimum Data Set is progressing with national data planned to flow from January 2016. The CYP IAPT programme is collecting outcome and activity data and working with services to drive up the quality of data collection.
19. Alongside this, there is the work that NHS England and Public Health England are doing to develop the Mental Health Intelligence Network (MHIN) – a comprehensive one-stop shop for data and intelligence enabling providers, commissioners and policy makers to understand and improve system performance – which includes a children and young people’s mental health strand. However this relies on good quality data collection. A key gap in data currently collected is the expenditure on CAMHS across agencies and areas (see below).

### Prevalence data

20. The last national community survey is now a decade old and excluded children under 5 years. Building on recommendations from the current and previous CMO Reports, work of the Child Health Outcomes Forum and the Health Select Committee Report, **the group propose that the Department of Health should commission of a regular prevalence survey of child and adolescent mental health every 5 years, giving particular consideration to including under 5’s and ages over 15** ensuring comparability with the previous surveys (ie B-CAMHS, 2004) and alignment with other key surveys such as What About YOUth?, the Health Survey England and The Adult Psychiatric Morbidity Survey which covers ages 16+.
21. In response to the growing international evidence base, the Department should consider expanding the survey to cover :
- new disorder codes (DSM 5) and conditions or issues that have grown in prominence since 2004 (eg eating disorders and the impact of social media and experiences of cyberbullying); and
  - the ability to filter data for characteristics such as ethnicity and deprivation or whether or not a child is adopted or in care.

22. This data collection should be linked to the CAMHS Minimum Data Set providing key data for developing local services to meet clinical need.

### Spending on CYP mental health

*“Greater recognition of the health economics of CAMHS services would help to demonstrate the importance of interventions in reducing impact on other systems such as health, education and social services. However, the lack of collaboration and joint working funding streams means that health, education and social care do not have a financial investment in the role that CAMHS can play in a young person’s life.”*

*A paediatric psychologist who took part in the Taskforce engagement exercises*

23. Historically underfunded and vulnerable to cuts because of its location within larger systems, the more recent context of austerity has resulted in extensive disinvestment in child and adolescent mental health services, with 25% cuts reported in some areas in 2013<sup>4</sup>.
24. In 2012/13 recorded NHS expenditure on child and adolescent mental health disorders was £0.7bn.<sup>5</sup> This was around 6% of the total NHS spend on mental health disorders in that year. There are known data quality issues with these figures: it is difficult to know whether spend has been captured accurately under children’s mental health, mental health or other children’s services.
25. There is no national information on current level of social care spend on children and young people’s mental health.
26. NHS England are improving their spending data from April 2015 so that it will be able to identify the overall spend in primary and community care as well as mental health services and specialist commissioning. This has been built into the NHS planning process at CCG level. This means NHS England will know both planned spend on mental health and actual spend against plan. **The Group propose that this activity is extended to cover children’s mental health spend by the NHS.**
27. This still leaves a gap on children and young people’s mental health local council spend. CMO’s Report 2013 made clear the investment in mental health services for children and young people should be proportionate to the associated health burden and that local authorities should prioritise against further disinvestment in children and young people’s mental health services.
28. **The group propose further work is done to improve understanding of child and adolescent mental health funding flows across health, education, social care and youth justice to support a transparent coherent whole-system approach to future funding decisions and investment.**

### Workforce data

29. While there are some areas eg in the North West that have significant data tracking workforce capability and skills, there is a lack of comprehensive national data on the CAMHS workforce. **The group propose that the Department of Health and the Department for Education work together with Health Education England, the Chief Social Worker and others, to design and commission an audit of the skills and**

<sup>4</sup> YoungMinds. Local authorities and CAMHS budgets 2012/13. YoungMinds 2013

<sup>5</sup> Programme Budgeting data, NHS England



capabilities of those working in targeted, specialist and highly specialist CAMHS to ensure the right staff with the right training are available in the right numbers.

## Outcomes measures

*“If data collects meaningful information that can be useful for clinicians and patients alike to monitor their progress, data collection becomes part of the therapy.”*

*A CAMHS psychologist who took part in the Taskforce engagement exercises*

30. There is evidence that tracking progress in therapy improves engagement and can reduce drop-out from therapy and lead to quicker and better outcomes. The use of outcome measurement, and other feedback tools, in clinical work with young people and families can track progress towards the goals that matter to them, as well to provide feedback to the therapist on the young person and family’s experience of therapy, change in symptoms and/or impact of the problem on life and general wellbeing. Such outcomes measures should be seen as clinical tools as well as indicators of performance and clinical accountability.
31. Frequent outcome measurement and reviews with young people are central to CYP IAPT. A lot of work on developing an approach to appropriate measurement and use of outcome measures has been done within CAMHS (CORC,<sup>6</sup> QNIC,<sup>7</sup> CORE<sup>8</sup>).
32. CYP IAPT has drawn on this work to provide a recommended set of measures (part of the CYP IAPT dataset) which offers a wide-ranging suite of possible patient-reported outcome measures (PROMs) for children, young people and parents/carers that are free to use along with guidance on their use (COOP document<sup>9</sup>). Data collected from a meaningful clinical use of feedback and outcomes data is likely to lead to more valid and reliable data, than data collected from high-level administrative processes disconnected from clinically-meaningful use.
33. In addition, the reporting of collated clinical outcomes is helpful for performance review and continuous service improvement. The CAMHS minimum dataset and CYP IAPT dataset include a range of outcome measures, including symptoms reported by the young person and their parent/carer, severity of impact, impairment and functioning. The ambition is to use patient reported outcomes and other data to help consider the impact of services. Many services are already using such data to benchmark their work and consider improvements (eg CORC, CORE, QNIC).
34. From 2016, data will start to flow from the CAMHS minimum dataset. HSCIC will start to assure data quality and develop and publish measures derived from the CAMHS MDS including outcome data from the measures suggested by CYP IAPT. This will enable robust monitoring to assess detailed trends in service quantity and quality over time and comparison of outcomes achieved across areas.

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<sup>6</sup> Child Outcomes Research Consortium

<sup>7</sup> Quality Network for Inpatient CAMHS

<sup>8</sup> **Clinical Outcomes in Routine Evaluation**

<sup>9</sup> CORC (2014), Guide to Using Outcomes and Feedback Tools with Children, Young People and Families

35. The CAMHS MDS will allow development of specific outcome metrics by mental health problem, activity and evidence-based interventions to support evaluation of the effectiveness of care commissioned.
36. **The group propose that the routine data collection of key indicators of child and adolescent mental health service activity, patient experience and patient outcomes should be co-ordinated and incentivised.**
37. CMO's Report 2013 recommended that the health and public health outcomes frameworks should include better integrated care as a shared goal which should feed into financial incentive systems.
38. **The group propose that the NHS and Public Health Outcomes Frameworks should work together to develop a metric that recognises children and young people's experience of their mental health care and incentivises effective integration of care to meet their needs.**

## Information sharing

*"I have been seen by a few different services, and the one issue I've found is that I have to repeat my story every time I see someone new. And personally I would rather they just access my file from a centralized database. I'd rather risk the idea of confidentiality and all of that for practically, when I'm in a state of need, and I really need someone to look at my notes, I might not be in the best state to explain everything, I'd rather there were a centralized database for people to be able to see my notes."*

*A young person who took part in the Taskforce engagement exercises*

39. This Task and Finish group agreed that there remains in many areas a need to change organisational culture and individual practice to ensure that appropriate information sharing, and seeking consent to share, is at the heart of good practice for supporting children and young people with mental health issues.
40. The Department for Education (DfE) is working with other departments across Government to strengthen and update the current 'Information Sharing: guidance for practitioners and managers'. The guidance provides an expectation of how professionals use, protect and share information, and encourages professionals to think about how they share information locally, as the team structures and processes used by professionals may vary across the country.
41. A myth-busting guide for agencies and individuals is also being created which aims to dispel common myths and barriers when sharing information. This myth-busting guide will form part of the revised information sharing guidance and will be available as part of a package, including the revised *Working Together to Safeguard Children* and 'what to do if' guide, which the Department for Education plan to publish in early 2015 to ensure information is shared appropriately, effectively and at the right time.
42. There is also specific work underway in the context of mental health through the CYP IAPT Integrated Services Group to develop a child or young person's passport as a way of facilitating information-sharing to improve care management in relation to individual cases. A specific question to capture children and young people's views on use of their NHS number to link information for the purposes of delivering more joined up care was included in the engagement work commissioned by the Taskforce.

43. Overall, there was a positive response from 2000 respondents aged between 14-24 when asked if they would be happy for information that they gave about a health service they had used to be shared in order to improve services and for this information to include their NHS number. Positive responses increased in the older age groups consulted. Many respondents reported repeatedly having to tell their story when they accessed a new service or met with a new worker and felt strongly that this needs to change. There was strong support for anything that could make interviewees personal experience of using services more joined up, including use of NHS numbers if this was helpful. The passport being developed by young people within the CYP IAPT programme is for the young person and professional to complete together, and it will be the young person's decision about whether they include their NHS number after they are made aware of the issues and the potential benefits.
44. There are a number of initiatives where local partners are working in innovative ways to share information and knowledge about a child and family resulting in the delivery of co-ordinated services. One such model is the Multi Agency Safeguarding Hub (MASH) which co-locates professionals from different agencies, including health, to act on and share information about the needs of the child in order to take timely and appropriate action. Necessary changes to children's social care systems have already been enabled in preparation for implementation of the Child Protection Information Sharing Project. This Task and Finish group would encourage local areas to look at how better integrated data collection might inform commissioning and service provision.

## Transparency, improvement and performance data

45. There is a CYP IAPT local management framework in development which uses the *Delivering With, Delivering Well* core service standards as the solid foundation for performance management. It includes very high level transformation markers and some challenging quality indicators.
46. The primary goal of data collected through routine outcome monitoring is to improve therapeutic intervention and inform supervision and service planning. However this data also plays a critical part helping us to understand service provision, patient experience and outcomes. Routine reporting will make data more accessible and transparent, allow benchmarking across services and help us to identify areas of good practice and demonstrate value for money. Over time the aim will be to share this data through the Mental Health Intelligence Network enabling local services and commissioners to use data and intelligence to improve pathways and better meet the needs of local populations (as part of Joint Strategic Needs Assessments for example).
47. Better information from national data sets, including the prevalence survey and CAMHS Minimum Data Set when these become available is critical to driving long term sustained quality improvement across education, health and social care.
48. Alongside this, local areas need to take responsibility for building the evidence to support their commissioning decisions. This should include sharing data about budgets and spend, and good information about local needs and assets. Commissioning support units and academic science networks can support commissioners to analyse local data, share best practice and pool knowledge and skills. In health, many providers are collecting significant data that can be used by commissioners – for example NHS benchmarking data, outcomes

data collected by members of CORC, the CYP IAPT datasets and outcome measurements and CAMHS currency data.

## Payment systems

49. Work on the development of possible payment systems in CAMHS is reaching a conclusion with advice to the Department of Health to be completed by March 2015. The work is showing that young people coming to services have needs that can be segmented into four groups based on the number of hours of help they receive. The care package and skills needed to help someone within each of the groups will vary according to the type of problem and how it affects them.
50. National consultation events on the current way forward are in progress. The current proposal suggests a currency model of resource-homogenous and clinically meaningful groupings of children and young people and supports the delivery of care in line with NICE guidelines. The proposed THRIVE<sup>10</sup> model for CAMHS would allow the embedding of these payment systems in an articulated model of need and choice.
51. **The Group proposes that future development of financial incentive systems across health, education, youth justice and children’s social care are aligned to drive improvements in children’s mental health outcomes.**

## Access and waiting times

*“The waiting time was very long. My status was raised to urgent when my weight reached dangerously low levels, so I was able to see someone more quickly, but I don't think this is an acceptable requirement for treatment...it made getting better much more difficult and put me in danger.”*

*A young person who took part in the Taskforce engagement exercises*

52. The NHS Five Year Forward View includes the following ambition:

*“We will publish meaningful and comparable measurements for all major pathways of care for every provider – including community, mental health and primary care. We also want to expand access standards to cover a comprehensive range of mental health services, including children’s services...we need new commissioning approaches to help ensure that happens, and extra staff to coordinate such care. Getting there will require further investment.*

*The Health Select Committee in its recommendations noted The Minister has argued that waiting time targets will improve CAMHS services but we recommend a broader approach that also focuses on improving outcomes for specific conditions in children’s and adolescents’ mental health.”<sup>11</sup>*

<sup>10</sup> Thrive – The AFC-Tavistock Model for CAMHS (November 2014)

<sup>11</sup> NHS Five Year Forward View, NHS England 2014

53. Building robust access systems improves the experience and seamless entrance to services and reduces waiting times: these are the factors critical to any effective CAMHS. Several pilots have already demonstrated the significant improved outcomes when access to services is swift.
54. Reducing waiting times to a point where children and young people access services at the point they present means that less time is spent on decision making about whether a young person could or should wait due to clinical need or risk and should remove referral meetings, as well as reducing the time spent on managing waiting lists.
55. Prompt access makes the process of working in collaboration with children and young people about what they want and when much more straightforward.
56. Young people and families need to have the experience that they are seen within a timeframe that suits them and that the focus is on their goals and outcomes. Introducing waiting time targets without considering the context of the access system and of young people's lives runs the risk of reporting only one part of a pathway, missing the relevance, quality and outcome of the contact.
57. This Task and Finish group agreed that the priority focus for CAMHS at this stage is not the setting of a blanket waiting time target (eg 18 weeks) but to ensure that a robust infrastructure allows the measurement of relevant parts of each different pathway (eg referral to assessment, assessment to treatment) and for that to be linked to the delivery of treatment in line with NICE guidelines and good outcomes. These metrics are being designed as part of the CAMHS MDS, and CYP IAPT obviously sets CAMHS off on the right track.
58. Ministers have made clear their ambition to deliver parity of esteem and there are examples of good practice: Birmingham Children's Hospital have developed a number of initiatives to manage access to their services so that the same access standards apply across physical and mental health, which has resulted in improved quality of care, reduced risk, increased referrer satisfaction, and more efficient and effective use of resources.
59. **This Task and Finish group proposes that in developing access standards for CAMHS, access to services is reported as the time to different events within a pathway, linked to delivery of NICE concordant treatment and outcomes at each step.**

## Empowering children and young people

*"Graphs were updated weekly to show my levels of depression which I later found helpful as it showed me that gradually over time my level of depression and anxiety had reduced and I could see I had made progress."*

*A young person who took part in the Taskforce engagement exercises*

60. The routine collection of feedback and outcomes information from young people and families, if used well, can facilitate better collaboration and shared decision making between therapists and young people and families.

61. There is good evidence that better use of data and technology improves patient experience, safety and outcomes. Use of apps and other digital tools can empower self-care; real-time record sharing can reduce care costs and halve waiting times.<sup>12</sup>
62. An example of this is the Diabetes UK Tracker App<sup>13</sup> which is available for free download on any Android or Smartphone and which allows young people to log and track their blood glucose, insulin, carbohydrates, calories, weight and ketones. Data can be viewed on daily or weekly graphs and can be exported by email to their healthcare professional if advice is needed. Young people can add photos of meals or other images to remind them of things that affect their blood levels and can save specific ‘talking points’, for example, dates of their healthcare appointments.
63. **The Group propose that NHS Choices content on mental health should link to the equivalent for children and young people– the Youth Wellbeing Directory<sup>14</sup> (endorsed by RCGP).** <http://www.chimat.org.uk/resource/item.aspx?RID=185576>

## Framework for improving IT

*“The best systems have the clinically meaningful use of data as the primary aim, supported by good IT and admin systems - this gives good quality valid data that is complete and integrated into clinical work - adding to the quality of the work, reducing drop out, and leading to better and quicker clinical outcomes. The failure of adequate IT systems to support data collection is one of the most significant issues of burden in gathering and using data both at the clinical level and for service evaluation and design.”*

*A mental health nurse who took part in the Taskforce engagement exercises*

64. Common standards need to apply to IT systems as part of providing the “electronic glue” that enables different parts of the health, social care, youth justice and education system to work together. This includes moving towards interoperability between IT systems.
65. The development of IT systems needs to support better use of feedback and outcomes information so that it is accessible and understandable by families and young people as well as clinicians. It tends to be this aspect that is overlooked in the development and provision of IT systems – but it is only if the data is used by clinicians in their clinics that practice will change and improve.
66. **The Group propose that children’s mental health services are included in the digital maturity assessment work being taken forward by NHS England.**
67. **Children and Young People’s Mental Health should be included in the work programme outlined by the National Information Board’s Framework for Action** <https://www.gov.uk/government/news/introducing-personalised-health-and-care-2020-a-framework-for-action>

<sup>12</sup> National Information Board : A framework for action 2014

<sup>13</sup> [www.diabetes.org.uk/How\\_we\\_help/Diabetes-uk-apps/Tracker-app/](http://www.diabetes.org.uk/How_we_help/Diabetes-uk-apps/Tracker-app/)

# A common language

*“Developing and implementing a shared language that is recognised and delivered by all providers would mean that a pathway would exist for each individual but can be managed by multiple services/disciplines.”*

*A CAMHS manager who took part in the Taskforce engagement exercises*

68. Differences in language and philosophy between the wider systems (health, education, social care) make cross-agency working hard and agreement on co-ordinated policies challenging.
69. **The Group propose the Taskforce agree a shared definition of key terms and how these should be interpreted in different sectors.**

# Members of the Data and Standards Task and Finish Group

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We would also like to thank the following people for their contributions to the report

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# Annex A: Health Select Committee Report on Children's and Adolescents' Mental Health and CAMHS - Extracts relevant to the work of the Data and Standards Task and Finish Group

## Information

2. The Committee is deeply concerned that the most recent ONS data on children's and young people's mental health is now ten years old, as up-to-date information is essential for the safe and effective planning of health services. We welcome the Government's commitment, made during the course of this inquiry, to fund a repeat of the ONS prevalence survey. It is essential that this survey is not a one-off, but is repeated on an ongoing basis. We recommend that the Department of Health/NHS England taskforce adds the issue of the quality of ongoing data to its terms of reference. (Paragraph 23)

## Information

3. Not only is there a lack of data on children and young people's mental health, *but also a worrying lack of comprehensive and reliable information about children's and adolescents' mental health services, including referrals, access and expenditure.* In the words of the Minister, CAMHS services have been operating in a "fog", and efforts to improve data availability have been subject to delays. This is unacceptable. Ensuring that commissioners, providers and policy-makers have access to up-to-date information about all parts of CAMHS services—from early intervention up to inpatient services—is essential. We recommend that this is a priority for the Department of Health/NHS England taskforce. (Paragraph 24)

## Outpatient specialist CAMHS services (Tier 3)

8. We heard from witnesses that national service specifications are required, to set out minimum acceptable levels of community CAMHS services, and we understand that Tier 2 and 3 service specifications are now being developed. We recommend that these specifications should set out what reasonable services should be expected to provide. They should cover specific clinical areas including ASDs, perinatal mental health, and eating disorders, as well services which currently fall between the tiers, including out-of-hours, outreach and paediatric liaison. We recommend that the taskforce should carry out and publish an audit of whether services are meeting these minimum standards. (Paragraph 116)

## Inpatient CAMHS services (Tier 4)

14. We believe that education is crucial to protecting the life chances of the especially vulnerable young people who need inpatient treatment for mental health problems, particularly as in some cases these admissions may last many months. It is essential that clear standards are set for the quality of education provision in inpatient units, and that there is clear accountability and ownership for ensuring that these standards are upheld. As a first step towards this, we recommend that OFSTED, DFE and NHS England conduct a full audit of educational provision within inpatient units as a matter of urgency. (Paragraph 166)

## National priority and scrutiny

25. It is clear that there are currently insufficient levers in place at national level to drive essential improvements to CAMHS services. These have received insufficient scrutiny from CQC and we look to review progress in this area following their new inspection regime. The Minister has argued that waiting time targets will improve CAMHS services but we recommend a broader approach that also focuses on improving outcomes for specific conditions in children's and adolescents' mental health. (Paragraph 249)

*The full text of the HSC report relating to the CQC is below:*

243. We were also told that "CAMHS receives very little if any scrutiny from the Care Quality Commission."

I have never seen a CAMHS team inspected in the same way as I see other parts of the public sector inspected. We have concerns about our Tier 4 providers. We are currently dealing with several complaints about them and we have shared them with NHSE, but we are the people writing the complaints letters and talking to the families; we are having the conversations behind closed doors about, "At what point do we go to the Care Quality Commission about a particular provider that we are concerned about?"

Our experience in Essex is that we have not had much involvement from CQC in children's mental health services. We have had more advice from our Ofsted colleagues, but really a very poor service from CQC. We have had to be very proactive ourselves in dealing with complaints to NHS England and sorting out the complaints and scrutiny ourselves...We have detected that they do not see it as part of their brief.

244. In response to this, the Minister told us that "the truth is that we do not have a full enough picture yet about the variability in quality around the country."<sup>291</sup> However, he believed new arrangements at the CQC would be stronger:

It may well have been a fair assessment, but I think it is changing. Now that we have someone with a dedicated responsibility for mental health ... I do not think there is any risk that children's mental health services will be ignored in the future. They are introducing a much more rigorous inspection regime ... That gives us an opportunity, as I indicated earlier, to put the spotlight on mental health and to really identify good practice, but also unacceptable practices, in a way we have never been able to do before.

245. The CQC have provided detail on their new inspection regime, which will from now on include an inspection of CAMHS services in all inspections of mental health trusts:

We began to pilot our new style inspections in NHS mental health services in January 2014, with a full roll-out from October 2014. The new style inspection defines core services for each type of organisation, which will always be inspected where they are provided. CAMHS has been designated as a core service for NHS mental health trusts. We have carried out twelve inspections using this new approach and will carry out a further four inspections this autumn.

246. However, the CQC were not able to give us information on which CAMHS services, or how many, had been inspected between 2009 and 2013.

## Annex B: List of Acronyms

ACE-V Accountability, Compliance, Empowerment- value

CAMHS: Child and Adolescent Mental Health Services

CAPA: the Choice and Partnership Approach

CORC: CAMHS Outcomes Research Consortium

CORE: Clinical Outcomes in Routine Evaluation

CMO: Chief Medical Officer

CQC: Care Quality Commission

CYP IAPT: Children and Young People's Improving Access to Psychological Therapies

HSC: Health Select Committee

MDS: Minimum Data Set

NICE: National Institute for Health and Care Excellence

OFSTED the Office for Standards in Education

ONS: Office for National Statistics

QNIC: Quality Network for Inpatient CAMHS

QNCC: Quality Network for Community CAMHS