

# **Joint SCHAT and SaTH Audit Report: Unmet Psychological Need in Paediatric Clinics**



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**Special and grateful thanks to all the doctors and nurses in paediatric clinics who gave up their busy time to collect this data and make this audit possible.**



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## 1. Executive Summary

Children and young people with chronic illness and/or physical health care needs suffer significant and extensive psychological distress, as do their families – sometime over many years.

The consequences of unmet psychological need lead to long term physical and psychological or mental health symptoms, lower educational achievement, poorer quality of life, psychosocial impacts on the family, and additional financial burden on health care resources.

There is currently a small, highly valued and effective Paediatric Psychology Service (PPS) locally which of necessity targets its limited resources. However, since its' establishment the number of children and young people requiring paediatric services has increased, as have the size of the multi-disciplinary teams caring for them. This has resulted in increased demand for psychological care with no additional psychological resources.

This audit concerning the extent and nature of this unmet psychological need across Shropshire and Telford & Wrekin Paediatrics within SaTH was carried out involving both the Acute and Community Trusts. The audit does not include data from Community Paediatrics. Significant unmet psychological need was identified. The outcome is described below.

### ***What We Did***

In the 3 months between October and December 2016 experienced paediatric doctors and nurses within SaTH collected data in all 156 paediatric clinics, involving 938 appointments, for 848 children and young people. This included:

- Which children they would refer if they could, including demographic details
- The nature, complexity, severity and duration of the problem(s)
- The type of psychological intervention likely to help

### ***What We Found***

In 191 of the appointments (24%) the child or young person was considered sufficiently distressed to warrant a referral. If this were extrapolated across 12 months this would equate to 813 appointments concerning a child or young person per annum.

This prevalence is similar to the percentage referred to CAMHS for mental health disorder. The CAMH services have an available resource of around 50 wte staff compared to around 3 wte staff in paediatric psychology services.

### ***Meeting the Need***

The audit suggests:

- Of the 191 appointments for a child who warranted a referral, in 56 of these staff indicated that the child (or staff treating them) could also be helped by case discussion and consultation with a paediatric clinical psychologist
- In 34% of appointments the child would be helped by evidence-based brief or early intervention and/or psycho-education, delivered by qualified and experienced psychology staff
- In 31% of appointments the child required a specific targeted therapeutic psychological intervention
- In 21% of appointments the child required an intensive therapeutic psychological intervention in the context of a systemic integrated approach across the multi-disciplinary and/or multi-agency teams involved with the child and family
- Unmet need is often longstanding, often involves more than one area of difficulty, and often requires more than one type of psychological intervention

NHS England recognises the key elements of a quality service are as follows<sup>1</sup>:

- ✓ There should be a paediatric psychology service available locally, with psychological resources integrated and embedded into paediatric MDTs and services to provide holistic care
- ✓ The service should have clear values & principles; be patient-centred, non-stigmatising, and have commissioners engaged with it regularly
- ✓ The service should be comprehensive & include resources for cyp across the range of diagnoses and paediatric populations, both in acute setting & community, with reference to national guidance and service specifications
- ✓ The service should be configured around ease of access and reaching out, including resources available for consultation, supervision, teaching and training
- ✓ There should be integrated and shared clinical and governance pathways
- ✓ The service should attend to the needs of cyp and their families, taking a systemic and family approach
- ✓ The service should be systemic to maximise reach and impact

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<sup>1</sup> Standards developed from "What Good Looks Like" 2016

- ✓ The service should include all tiers/levels of provision, including emphasis on early intervention and prevention as well as providing care further along the windscreen of need, and provide a range of evidence-based psychological interventions
- ✓ The service should include emphasis on outcome measurement, research and audit processes so that impact can be evaluated
- ✓ The service should ensure that the service users voice is central & involve service users throughout evaluation of service delivery & development

## ***Conclusions and Proposed Way Forward***

This audit identified significant unmet need in this psychologically vulnerable group, within Paediatrics across SaTH. This is likely to be an under-estimation of need since the current audit did not include Community Paediatric services or neonatology, and previous audit data indicated that medical staff tend to significantly under-estimate psychological need.

Many children and their families are enduring complex, severe and long-standing psychological difficulties and distress which would respond positively to evidence-based psychological interventions and approaches.

The highly regarded PPS is currently inadequately resourced to meet this need.

Proposals are made to increase the PPS resource, which in turn will enhance the psychological knowledge and skills of staff in paediatric MDTs and services.

To take this forward there is a need to establish a task and finish group of key stakeholders from the relevant Trusts along with colleagues in commissioning to explore service development requirements.

## **2. Background**

The Paediatric Psychology Service (PPS) was first commissioned in 2008 and launched in September 2009. The service has 1.8 wte staff who are jointly commissioned by Shropshire and Telford & Wrekin, plus some additional capacity commissioned or funded separately by RJAH (0.6 wte) and by Powys. (This resource was identified from slippage funding and so was not commissioned on the basis of recommended national service specifications or KPIs.) It also has some additional capacity from the Lead Consultant Clinical Psychologist/Professional Lead, who works clinically in the service and supports the operational management of the service alongside the Team Leader (appointed June 2017).

The number (population) of children and young people aged 0-19 years across Shropshire and Telford and Wrekin (2011 census figures) are 111,796<sup>2</sup>. Shrewsbury and Telford hospitals cover this population in their catchment, but also additional children from Powys under SLA contracts.

At launch in 2009 commissioners agreed with the clinical Steering Group<sup>3</sup> that the most efficient and effective service model would be an integrated one, with paediatric psychologists becoming members of established teams or specialties. This would enable evidence-based psychological practice and skills to be disseminated throughout the multi-disciplinary teams. The importance of enabling patient access to the service based on clinical need, including early intervention and prevention, was also recognised. The service developed some key principles underpinning the service implementation:

- ✓ **The service should offer high quality provision to targeted areas rather than attempt to offer generic services across all of paediatrics**
- ✓ **The service should be accessible to the children, young people and their families using it**
- ✓ **The service should be patient-led**
- ✓ **The service should include the families and siblings of the children and young people accessing it**
- ✓ **The service should be non-stigmatising. Therefore the paediatric psychologists should be integrated members of the relevant multidisciplinary team**
- ✓ **The service should provide prevention and early intervention activity and not be based on a “casualty based referral system”**
- ✓ **The service design should include robust prospective evaluation and audit processes including routine outcome measurement**

This service model is strongly supported by recent national guidance and best practice (What Good Looks Like, DCP 2016). We were aware that such a small resource would be overwhelmed by demand if the service model was generic and available to all of the paediatric population, and so a decision was made to target the service. Decisions were made to allocate finite capacity/resource to specific teams, based on agreed criteria (for further details see early evaluation and subsequent review reports).

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<sup>2</sup> Shropshire population aged 0-19 is 68,196. Telford and Wrekin has a 0-19 population of 43,600

<sup>3</sup> This was an inter-agency group established at launch, with agreed ToRs to ensure implementation of service objectives, provide a link between key stakeholders and collate feedback, ensure dissemination of protocols and pathways, assist in contract monitoring and receive annual reports, to monitor progress and address operational/strategic issues, and to provide a consensus view on priorities for service development and resource allocation. The Steering group ceased meeting during 2011 due to lack of commissioner engagement.



Therefore the service is limited and targeted to the following specific areas of need (selection of targeted areas was supported by evidence from national KPIs but not based on these exclusively) :

- Diabetes
- Paediatric Oncology & Haematology
- Palliative Care
- Where there is an allocated Community Children's Nurse (CCN)
- Cystic Fibrosis
- Muscular Dystrophy
- Chronic Constipation MDT (Telford only)

There is clear national evidence that patients interests are best served when the care approach is seamless and integrated/shared across agencies and professionals. Therefore the PPS service aims to contribute effectively and efficiently to the development of a consistent, shared and agreed/negotiated care plan for the patient, which ensures (as far as possible) a continuity of approach across the various services working together with the patient/family, and to reduce the risk of inconsistency, difference in advice given, and confusion/rifts between services or approaches. Referral criteria are based on psychological need which relates principally to the child's physical health condition. Each paediatric team with identified psychology resource available to them is required to prioritise cases internally within the available allocated resource. The PPS does not therefore run any waiting lists, and both the medical MDTs and their patients can access the service on the basis of need, using a "step-up, step-down" model of episodic care. The psychologist is a known and familiar member of the MDT in most cases, which reduces stigma (and DNA rates) and enhances positive engagement.

However, since 2009 the numbers of children and young people requiring treatment within the MDTs have increased substantially, and therefore the MDTs themselves have responded by developing and have grown in size, within acute paediatrics. This has meant that the staff numbers requesting psychological input have increased substantially. However, there has been no corresponding growth in the available psychological resource or staffing. In the absence of a joint inter-agency paediatric strategy, and common agreement regarding service priorities and development, there has been no shared planning forum where the psychological resource available/needed has been reviewed alongside other inter-agency team resources. This has led to increasing and significant frustration regarding the relative lack of psychological resource, alongside growing demand both in terms of complexity of cases presenting and overall numbers of children and young people who are perceived as requiring psychological input.

There have been various national recommendations and benchmarking data suggesting increases in psychological input are necessary and required, delivering evidence-based interventions with recognised efficacy, for children with a range of physical health problems. The PPS has noticed that increasingly teams are forced to refer patients with greater complexity/severity of needs, at the cost of those with early intervention and prevention needs – which means that interventions and the associated liaison and consultation requirements are likely to take longer, and potentially children will develop difficulties which are preventable, and not be able to access the specialist psychological support they require. Teams are pushed into prioritising requests for face-to-face psychological interventions at the cost of time spent consulting on cases with the psychologist, which has reduced time spent with colleagues disseminating psychological approaches or perspectives – something which (independent) service evaluation highlighted as being particularly valuable and effective, and which we know from the established evidence-base is one of the most effective and efficient ways to deliver psychological provision.

In addition, MDTs are now struggling to prioritise cases requiring psychological input within what they feel is an insufficient resource. Both Shropshire Community Health Trust (SCHT) and the Shrewsbury and Telford Hospitals (SaTH) have recorded these challenges in their respective departmental risk registers. There continues to be ongoing and increasing concern about levels of unmet psychological need presenting in SaTH paediatric clinics, including issues around efficiency, financial cost and Quality of Life impacts, and ongoing lobbying for more and wider provision across paediatric services both in the community and the acute sector. There is widespread agreement that the integrated service model is highly valued, has a national evidence-base, and is clinically appropriate; recently NHSE has supported the production of “What Good Looks Like in Psychological Services for Children, Young People and their Families” (2016) which includes specific recommendations and standards for paediatric psychology services nationally. Teams continue to be aware that they have a finite and limited psychology resource allocated to them, and that they need, therefore, to discuss and consider how they utilise that resource on an ongoing basis. A key tension remains between wanting more capacity for direct interventions, and recognising the value of and need for indirect levels of intervention (e.g. consultation). Given the value of the resource available, and within the context of national recommendations that psychological input be accessible to children with physical health conditions, it is vital to estimate and ascertain the likely level of psychological need and the resource it will require going forward, since once the service has been discussed with families, or a family has engaged, it is often not possible to withdraw that provision even if the need does not wholly meet the MDT/service criteria.

There is therefore a need to collect data regarding what the level of unmet psychological need currently is, including whether this need could be met by direct interventions, or the provision of

indirect consultation and support by paediatric psychologists. It is becoming increasingly recognised that children with chronic physical health conditions do have significant psychological issues without a mental health diagnostic code. However, the impact of their difficulties has far-ranging consequences including non-compliance, increasing need for unnecessary medical interventions, admissions and diagnostics, costing the NHS. Physical ill-health and its psychological sequelae also have significant psychosocial consequences, many of which are the “hidden iceberg” which will potentially have long term consequences for the young people’s future. Senior paediatric consultants and MDT staff have fed back their view that there is a need to expand the PPS to ensure that patient’s holistic needs are met, and psychological issues are addressed before they become major health and social problems. Early intervention and psychologists embedded in clinics also ensure that any stigma is addressed/reduced, and engagement is promoted.

Therefore we agreed to undertake a joint audit with SaTH which tries to capture data regarding unmet psychological need in children and young people presenting within all paediatric out-patient clinics at SaTH (across both Royal Shrewsbury Hospital and Princess Royal Hospital, Telford) during the audit period (October to December 2016). The audit captures estimates made by experienced doctors and nurses running the clinics regarding the numbers of patients attending clinics who required a direct psychological service were it available, numbers who would benefit from indirect input via the medical/paediatric staff, and data about specific patient need and presentations. It should be noted that from previous audit we know that medical staff, particularly when in busy paediatric clinics where they are focusing specifically on physical or biomedical symptoms, tend to significantly under-estimate psychological need, particularly if the psychological distress is more ‘systemic’ and involves the family and/or interfamilial relationships rather than just be manifest in the presenting child. They may also be less likely to perceive significant psychological distress in babies or toddlers (for example due to difficulties in attachment and bonding, or difficulties which manifest as behavioural but which are actually related to emotional or family/life event challenges).

In previous service reviews patient and service-user feedback has consistently indicated that the service is highly valued and effective for those who can access it, but that concerns were raised by many regarding the perceived inequity of service delivery due to the targeted nature of the service. They feel there needs to be access to specialist provision regardless of condition. The vast majority (92%) of stakeholder respondents also felt the service should provide prevention and early intervention and not be based solely on a referral system with thresholds for severity or complexity. Patient groups overwhelmingly supported the current service model. Commissioners have previously stated that

*“changing the service model in an attempt to ensure equity across service areas is likely to undermine the clinical effectiveness of current service delivery and*

*raise the threshold for patients.... and result in fewer children receiving a service than currently, and only when having higher levels of emotional distress related to their physical condition.”*

Between 10 and 30 percent of children and young people in the UK have a chronic illness or physical health need (Kush & Campo 1998) and 10 percent of all young people under age 19 years are admitted to hospital every year (DoH 2000). Children and young people with health conditions (and their families) experience 4 times more psychological distress than their healthy peers (Hysing et al 2007). The impacts are extensive (for further detail see “What Good Looks Like” 2016). Given the targeted nature of the current paediatric psychology service, ***we know that many children in Shropshire and Telford & Wrekin have no access to a service that aims to meet this need.*** This audit attempts to capture and quantify some of the unmet psychological need presenting within our local paediatric clinics, in order to inform future service review and developments.

Grateful thanks must be extended to all the doctors, nurses and other paediatric staff who gave up their busy time in clinics to collect this data and enable this audit to go ahead.

### 3. Project Group

The audit was discussed between service leads and it was agreed that a joint approach was required. Therefore the proposal was submitted to both Trusts (SCHT and SaTH) via their Quality and Safety Committees. The data collection tools were developed within SCHT and piloted within identified MDTs, and changes to the data collection forms made to ensure standardisation of response.

Name	Job Title	Role within project (e.g. audit lead, supervisor)
Hilary Griggs	Lead Consultant Clinical Psychologist, PPS	Project lead
Dr Andrew Cowley	Clinical Director, Paediatrics (SaTH)	SaTH lead
Dr Beth Sherratt	SHO, SaTH	Data collection
Michelle Bramble	Clinical effectiveness lead	Project support

## 4. Aim

To identify areas of unmet psychological need within all paediatric out-patient clinics in The Princess Royal Hospital, Telford and the Royal Shrewsbury Hospital, Shrewsbury over a specific period of 3 months (October to December 2016). To understand the type of unmet need reported, in terms of complexity and severity, and what interventions medical staff think would be required to address them.

## 4. Objectives

- To identify how many patients would require a service were it to be available, and their demographics
- To identify perceived need for consultation services
- To identify which clinical populations (based on diagnosis) require psychological input
- To identify what kind of psychological need is being identified as a service gap
- To ascertain levels of complexity (of intervention) required
- To ascertain levels of psychological distress that are currently not being addressed
- To ascertain broadly what kind of psychological intervention paediatricians/medical staff feel would be required
- To undertake a pilot in order to ascertain whether paediatricians/medical staff identify the same or similar unmet need compared to paediatric psychologists using inter-rater reliability tests
- Having identified unmet need to share this data with commissioners and senior managers in order to support service development

## 5. Standards

Standard	Source	Any Exceptions
What Good Looks Like in Psychological Services for Children, Young People and their Families (2015) Division of Clinical Psychology, BPS and supported by NHSE	BPS, DCP Faculty for Children & Young People	No Exceptions

Standard	Source	Any Exceptions
Paediatric standards of care – various national documents relating to specific conditions e.g. Cystic Fibrosis, Diabetes, JIA, oncology, rheumatology, cardiac, cleft presentations, and others		No Exceptions

## 6. Sample

Paediatricians and/or senior/lead medical MDT staff completed the audit tool for each paediatric clinic they undertook between October and December 2016, reporting on all children and young people seen or reviewed in that clinic. Some clinics in the Robert Jones and Agnes Hunt Hospital (RJA) and run by paediatricians working across sites also collected data. The final data set included 156 paediatric clinics, and a total of 983 appointments for children and young people.

It needs to be noted that some children and young people may have attended more than one clinic in the audit period, and the data collected did not allow for exclusion of these children, since clinic staff could not necessarily identify children who had attended a previous clinic in the audit period. Constraints of capacity meant that it was not possible to retrospectively look at the data and extract individual children or young people who had attended more than once. We do know from SaTH data, however, that during the audit period 87% of the children and young people attending paediatric clinics attended only once. In 11% of cases the child attended twice, and only in 1% of cases did the child attend either three times or four times. This means that only 110 children attended more than once, while the remaining 737 children attended on one occasion only.

It is also important to note that we do not expect there to be any significant seasonal variations for most specialities, with the possible exception of respiratory clinics – although these numbers are extremely small.

During the pilot phase the paediatric psychologists completed the data collection tool alongside their colleagues, and any confusion regarding what was being asked for was clarified. Some changes were made to the tool to ensure consistency of data capture across teams.

During this period the MDT teams were keen to try and test out whether their appraisal or estimation of psychological need in the child was the same/similar as that identified by the

psychologists. The original proposal had included some inter-rating reliability testing to explore this issue – whether medical staff ‘correctly’ identify psychological need or presentation (both in terms of its existence and its type), and if so, whether they see that need as having the same levels of complexity as psychologists. However, it quickly became apparent that this part of the proposal would not be feasible – some medical staff work routinely with paediatric psychologists in MDTs and therefore have now developed a much greater awareness than others regarding what presenting issues might have a psychological basis, and indeed how that need might be formulated and responded to, than others. To explore this would have necessitated comparing the understanding of (sometimes complex) psychological presentations in staff who have had considerable experience of working with paediatric psychologists over several years, with the understanding of staff and/or teams who have not. This clearly would not yield comparable results. Without a psychologist in every paediatric clinic during the data collection period, it was therefore unrealistic to try and compare scores or to try and ‘validate’ whether or not identified (but unmet) psychological need was understood in the same way across medical staff. Nevertheless, given that most paediatric clinics have at least one member of staff who has routinely worked with a paediatric psychologist – albeit in another MDT setting – and there are increasing levels of awareness nationally about the impact of psychological factors within paediatrics via exposure in medical training and CPD about how psychological distress may present. We were therefore confident that levels of need would be identified with fair degrees of accuracy. Nevertheless, we know from previous audits that medical staff are more likely to under-estimate psychological need, rather than over-estimate it, and therefore the figures in the data capture are likely to be under-estimates of need. Previous local audit has suggested that medical staff tend not to sufficiently recognise, or to under-estimate the impact of, issues such as ‘systemic’, historical and/or family difficulties, and psychological presentations around difficulties with attachment and identity/self-esteem. For example, they might struggle to adequately recognise early signs of psychological distress in a baby or toddler as readily as a psychologist embedded in the clinic setting.

## **7. Data Sources and Methodology**

A data collection tool was developed which asked clinicians in all paediatric clinics to identify:

- ✓ The date of the clinic
- ✓ The venue of the clinic
- ✓ The type of clinic (i.e. general or specialist)
- ✓ The name(s) of the staff running the clinic
- ✓ The total number of patients seen in the clinic
- ✓ The number of patients in the clinic which the lead clinician(s) would have referred to a paediatric psychology service had it been available

- ✓ The number of patients in the clinic for which psychological consultation would have been valuable

For each child that they would have referred had a service been available (i.e. with unmet psychological need) the following data was required:

- ✓ The child's initials and age
- ✓ The child's medical diagnosis (using codes provided)
- ✓ The child's psychological problem (using codes provided)
- ✓ The complexity of the psychological problem (codes provided)
- ✓ The severity of distress or psychological disturbance (codes provided)
- ✓ The duration of the psychological problem
- ✓ The kind of psychological support or input they felt would be required (codes provided)

In clinics where there was already some psychological service available a modified tool was used to enable the collection of data about children who exceeded the available resource.

Copies of the data collection tools are available in the appendices.

Having designed the tool the paediatric psychologists piloted their use in MDT clinics that they attended, to test how consistently the tool was used. Some minor modifications were made to ensure that the data was entered consistently.

The paediatric clinical director sent an email to all paediatric staff emphasising the requirement for all clinics to collect and submit data during the audit period, and raised the issue in paediatric staff meetings leading up to the audit period. Reminders were also sent. Key nursing staff were identified to ensure forms were completed and submitted, and an SHO was identified to collate and enter the data onto an excel spreadsheet.

The project team are confident that all paediatric clinics were sampled within PRH and RSH. Clinics at Robert Jones Agnes Hunt Hospital were not routinely included, although some consultants working across sites (mainly in neurology and neuro-disability clinics) collected data at RJAH.

## 8. Results

During the data collection period information regarding 983 appointments for children or young people was gathered, within 156 paediatric clinics, between October to December 2016.

Data about children already known to the PPS was not included.



Data collected included both total numbers of children with unmet psychological need, and specific details about each child – including what the perceived need was, what their medical condition was, their age, the duration of the psychological need, its severity and complexity, and feedback asking what kind of psychological input might be required (this may not reflect what a paediatric psychologist might recommend, but gives an indication about what medical colleagues feel might be helpful at referral stage).

We also asked whether a referral for direct intervention would have been made (were the service to be available) or whether or not consultation (including teaching or training or case discussion at the MDT) might be helpful. Whilst consultation was felt to be helpful (56 cases or nearly 30%) most colleagues felt that a direct service was required.

Clearly some children and young people were not felt to have unmet psychological need. The total number of children attending clinic was recorded alongside those who the team felt they would have referred, had a service been available.

In some cases the record captured that were other mental health services already involved (such as CAMHS) although these were extremely small numbers (around 5 cases). Looking at the reasons for referral it is clear that medical teams understood the difference between psychological presentations and psychiatric ones since they discriminated which ones would be most suitable for CAMHS, and there is a good understanding of the difference between paediatric psychology (needs concerning the relationship between the psychological and physical wellbeing of the child, including the emotional and behavioural impact of the disease and its treatment) and formal mental health provision for cases with formal psychiatric diagnoses or associated risks.

There have been no large-scale estimates or surveys which look specifically at the levels of **psychological need** in general paediatric populations, although in some specialist medical areas this has been explored (Cadman et al 1987; Lavigne & Faier Routman 1992; Meltzer et al 2000). **These studies have consistently shown that while the majority of children with a medical condition or chronic illness do not have a psychiatric disorder, a significant minority do have difficulties with adjustment and/or symptoms of psychological distress** (Edwards & Titman 2010). Subsequent studies have focused on identifying risk factors associated with increased rates of psychological difficulties (Sloper 2000). There is good evidence that increased rates of emotional problems, rather than 'behavioural' problems are seen amongst children with chronic illness or disability (Glazebrook et al 2003). If we look at prevalence rates of psychiatric disorder, we find that nearly a quarter (20%) of children experience a mental disorder during the past year, and about 30% during their lifetime. Anxiety disorders are the most common conditions. The ONS (2000) report that among children with life-threatening illness (rather than the more general paediatric population) 26% reported

experiencing emotional disorders and 19% with conduct disorders – and concluded that 1 in 6 had a diagnosable mental health disorder.

The unmet need recorded in this audit was identified on the data collection tool by the lead or senior doctor in 158 cases, by the clinics nurses in 18 cases, and were not recorded in 14 cases.

We agreed to present the results regarding:

- overall numbers of children presenting with unmet psychological need
- their demographics (age)
- how many were from particular clinic type or with particular broad medical diagnoses
- Estimated complexity of psychological need (estimated by doctor/nurse on basis of brief discussion in clinic)
- Estimated severity of psychological disturbance (as above)
- Estimated duration of problem (as above)
- Numbers of children and young people with more than one presenting problem
- What type of psychological support was needed, as ascertained by the medical profession

It may be possible to interrogate the data further although this would require additional resource to undertake more advanced statistical analysis than is practical at this stage.

### **Overall Numbers of Children Presenting with Unmet Psychological Need in Paediatric Clinics**

In 190 appointments the child or young person was identified as having unmet psychological need (24%) which would have precipitated referral to a paediatric psychology service were it to be available. In only 5 cases were these children or young people identified as requiring formal CAMHS provision – and in these cases CAMHS were already involved. This confirms the findings of previous surveys of both stakeholders and service users; these children and young people have increased rates of psychological difficulties (Sloper 2000), especially the more 'emotional' type of problems rather than 'behavioural' ones (Glazebrook et al 2003). In the evidence base there are clear differences between the referral patterns in CAMHS and psychological services in a medical setting – referrals in physical health settings and contexts are more likely to be for issues such as difficulties in managing adherence to treatment or the

child's and their family's adjustment to their medical condition rather than problems that fit within the usual mental health/psychiatric diagnostic model. Working in a medical setting often means seeing children and families in a much less structured way than in a mental health setting, and fitting service provision into the existing medical framework of care. (Edwards & Titman, 2010).

In some cases we were able to examine unmet psychological need in clinics/teams where there is already some limited psychological input, but where that provision falls short of national recommendations. The paediatric diabetes team is the key example of this.

We also asked respondents whether some case discussion and/or consultation with a paediatric psychologist would have been useful. The percentage of appointments where case discussion and/or psychological consultation was identified as would have been useful was in 56 cases (29.4%). Having easy access to routine and regular psychological consultation is one of the most efficient and effective ways to ensure that treatment plans are psychologically-informed, so that the MDT is supported to consider a wide range of psychological, emotional, social, cognitive, systemic and developmental factors and generate hypotheses to plan and test different ways of working and formulating on behalf of the child and family. This kind of service provision also assists in promoting good psychological care as part of the Trust's clinical pathways for all children, even those not directly involved with a psychological service.

It should be noted however that the data also indicated that in all cases direct referral of the child and/or family was seen as preferable – this may be understandable in the context of limited knowledge, experience or awareness regarding the value of such consultative services, and the fact that stretched paediatric staff will perhaps inevitably prefer someone to see a child directly rather than find time in a busy schedule to seek consultation in order to change or modify their own intervention with the child. For this reason it is vital that regular psychological consultation is made readily available in places and forum where staff are already discussing their cases and treatment plans – such as in MDT meetings, rather than setting up new forum for this to take place except for those staff who can commit to this kind of supervisory support and advice.

## Demographics (age)

Currently there are no national agreed figures which capture data regarding **psychological** need in paediatric populations, although the ONS does provide data regarding **mental health** problems (based on psychiatric diagnoses). The ONS tells us that 1 in 10 of all children have a diagnosable mental health problem, although this is likely to be a significant under-estimate of need given the data only refers to children between ages 5 years to 16 years. After 16 years there is a steep rise in epidemiology. The ONS tells us that 1 in 6 children with a physical health problem had a diagnosable mental health disorder (2000). If we look at prevalence over a year, the figure is nearer 20 percent of all children. We also know from surveys that many

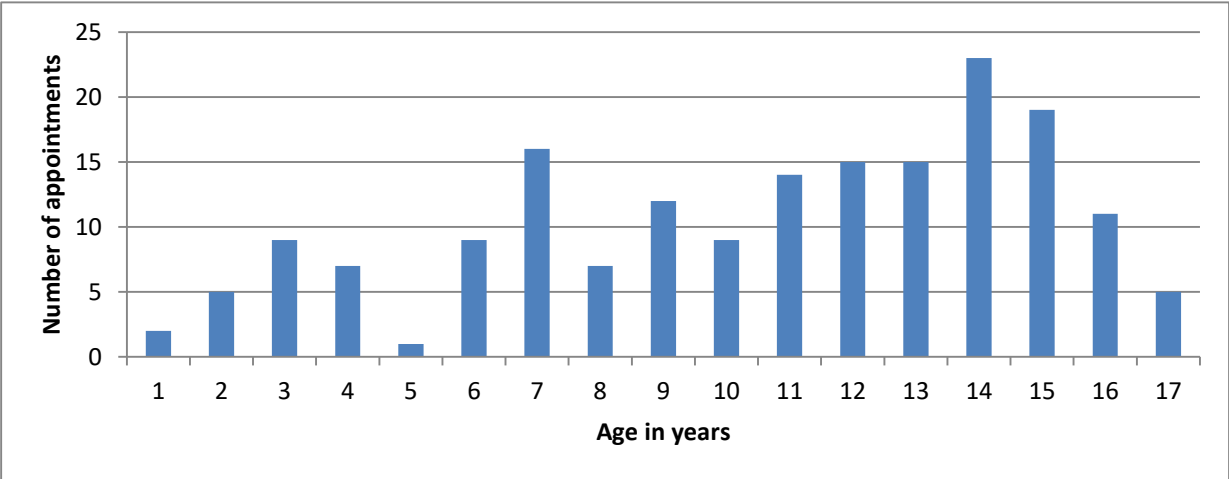
children and young people with diagnosable mental health problems do not access mental health or psychological services – around 76 percent of 5-15 year olds. These figures also exclude all the early intervention and prevention issues – and in paediatric populations these issues are noticeable, with the evidence clearly and repeatedly demonstrating the effectiveness (clinically and financially) of intervening early and not waiting until difficulties are chronic. Whilst effect size may seem small in child and/or paediatric populations, we need to recognise the long-lasting effects over the course of their lives – making relatively small but positive impacts worth pursuing.

From our data it is clear that the estimated unmet psychological need matches roughly that that we would expect were we to look at normative mental health data – with around a quarter of children and young people presenting with difficulties, sufficient to prompt a trained paediatric professional to refer to a specialist service.

**All children with unmet need: Age Spread**

Our sample tells us that unmet psychological need was identified across the age range, but that unmet need increased with age. It should be noted that given that family factors were included in the survey, the need was not based purely on the need in the individual child, but within the presentation at clinic of both the child and their parent/carer/family.

**Table 1: Age spread**



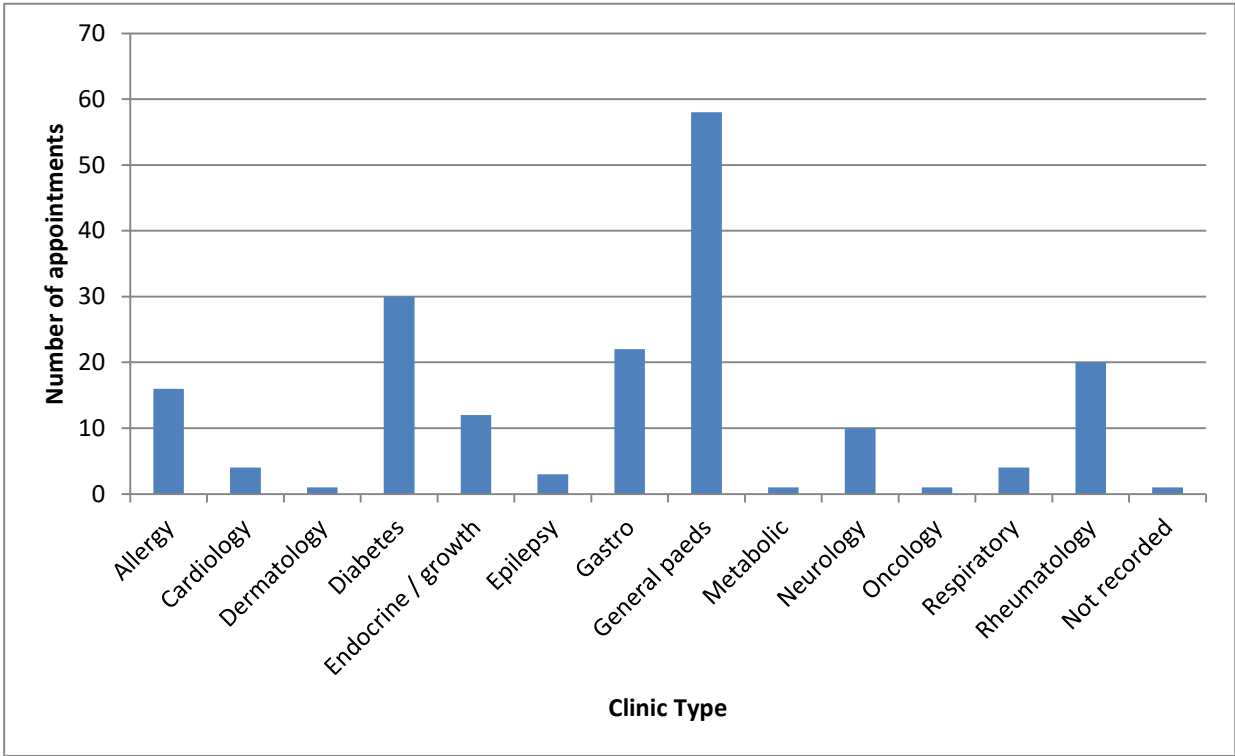
**Type of Clinics and Medical Diagnoses**

We asked respondents to indicate what type of clinic they were identifying children in. Some clinics were general paediatric clinics where a range of medical diagnoses and difficulties were presented; others were specialist clinics where specific populations of children and young people were seen. The ONS tells us that some medical diagnoses are more likely to be

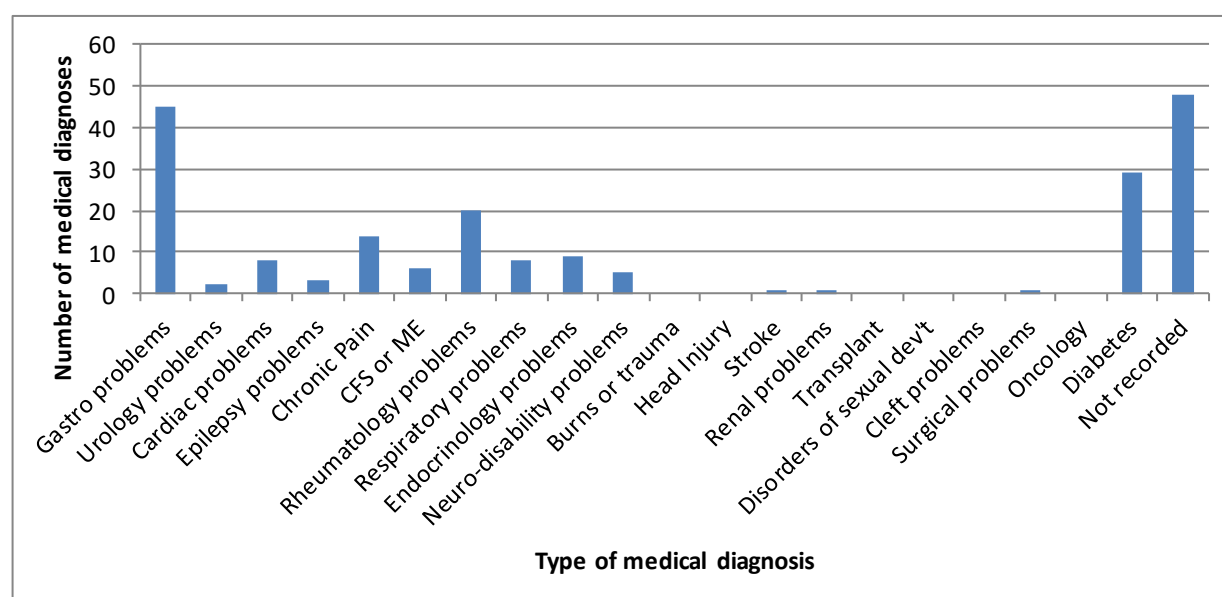
correlated with *mental health problems* as reported in national surveys. The areas with higher incidence of mental health problem were epilepsy, functional problems (soiling, wetting, feeding etc.) muscle or neurological conditions, kidney or gastro problems, congenital problems, allergy and asthma, diabetes, respiratory problems, ear-and-eyesight problems, blood disorders, heart problems and eczema. Children with life-threatening illness were also at increased rates of risk. Many of these have no psychological resource locally.

All these categories were represented in our sample.

**Table 2: All appointments for a child with unmet need: type of clinic**



**Table 3: All appointments for children with unmet need: types of medical diagnosis**



The areas where the PPS already delivers some psychological service reported relatively low rates of unmet psychological need (e.g. oncology). However, the unmet psychological need identified by the **paediatric diabetes team**, who do have access to limited psychological intervention (and therefore are experienced in both identifying it and understanding the efficacy of psychological intervention) is one of the highest estimates. This reflects the urgent need for some additional resource, which has been highlighted regularly by the team as falling well short of national recommendations.

We looked particularly at clinics where more than 10 children or young people were identified in the 3 month data collection period, given that this number of referrals would give an approximate indication of a caseload which would warrant at least 1 day per week psychology resource, were those referrals to be responded to effectively (this is based on the evidence from current service delivery).

The **clinics** which reported these levels of unmet psychological need were allergy, endocrine and growth clinics, gastro problems, general paediatric clinics, and rheumatology.

The **medical diagnoses** of the children and young people identified as having unmet psychological need were those with gastro problems, chronic pain, rheumatology diagnoses, diabetes and some clinics where the speciality was not recorded (these might reasonably be added to the “general paediatric’ clinic data.) Gastro and diabetes were especially notable in this respect.

It needs to be noted that although in some other clinics the numbers of appointments for children with unmet psychological need were felt to be relatively low, this may indicate the

lower incidence of those medical problems in the paediatric population. In terms of percentages within those clinics the number with psychological need may therefore be much higher than in other populations. We would need data about the total numbers of children seen in those clinics across the year to explore this further. In addition, those children – for example with cardiac problems – may represent greater levels of ‘psychological threat and distress’ (in other words chronicity and complexity) than children presenting in other paediatric clinics.

### **Type of Psychological Problem Identified**

We asked respondents to code what kind of psychological problem they felt the child presenting in the clinic had, providing them with a list of common psychological presenting issues.

It should be noted that some children and young people presented with more than one psychological problem (for figures about multiple problems see table 11). The problem list were not the conventional mental health diagnoses reported on by the ONS, but were those more typically seen by paediatric psychology services across the UK. These problems are ones which are known to have potentially lasting impacts on the child and their family, can represent significant challenges for the treating team, and for which there are known evidence based psychological interventions.

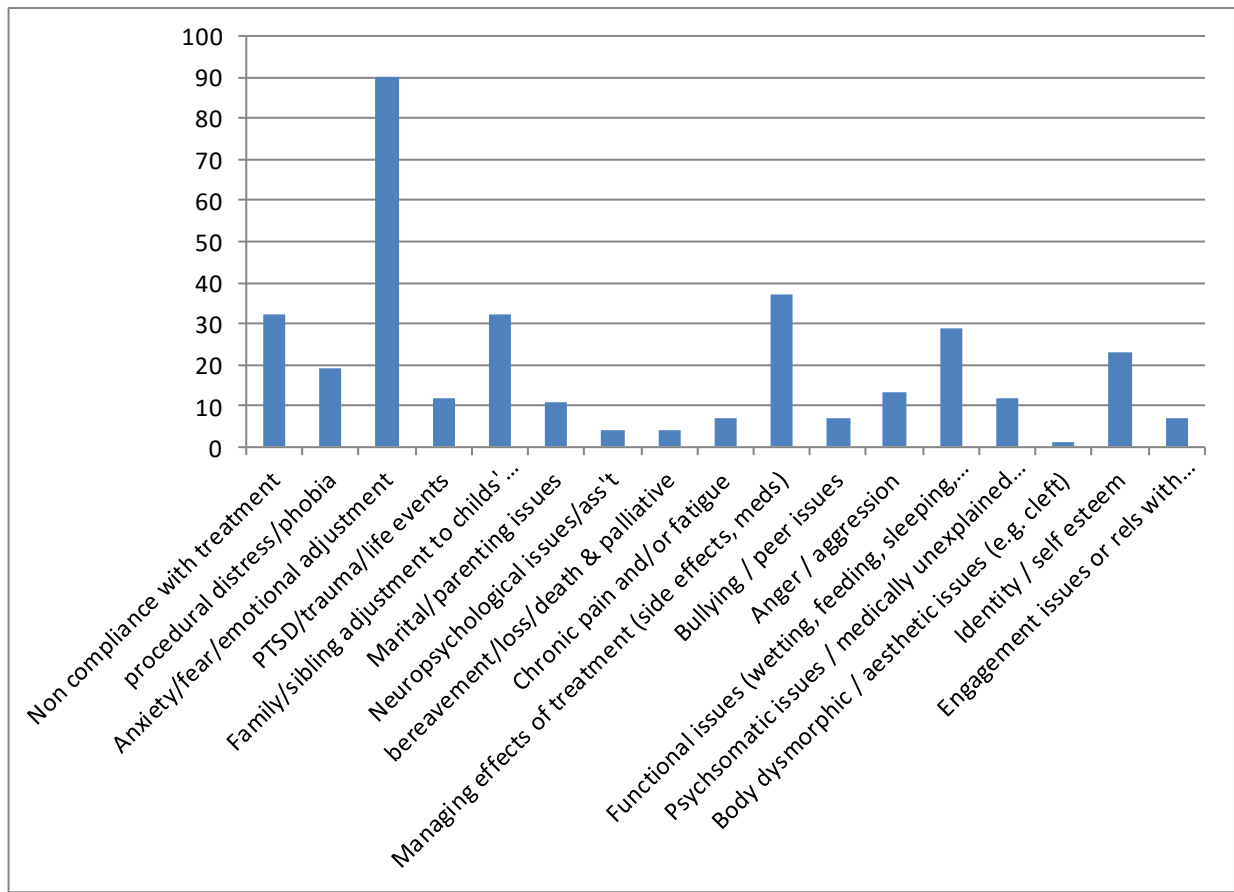
The data tells us that the most prominent psychological issues (those reported for over 20 children, or around 10 percent) were non-compliance with treatment, anxiety/fear/emotional adjustment, adjustment to the child’s condition or treatment, managing the effects of treatment, functional issues, and problems with self-esteem or identity. The largest category was emotional adjustment.

### ***Number of psychological conditions reported for all children (some had >1)***

Non-compliance with treatment	32
Procedural distress/phobia	19
Anxiety/fear/emotional adjustment	90
PTSD/trauma/adverse life events	12
Family/sibling adjustment to child’s condition/treatment	32
Marital/parenting issues	11
Neuropsychological issues/assessment	4
Bereavement/loss/death & palliative care	4
Chronic pain and/or fatigue	7
Managing effects of treatment (side effects, meds)	37
Bullying / peer issues	7
Anger / aggression	13

Functional issues (wetting, feeding, sleeping, soiling, self-care)	29
Psychosomatic issues / medically unexplained symptoms	12
Body dysmorphic / aesthetic issues (e.g. cleft)	1
Identity / self esteem	23
Engagement issues or relationships with professionals/systems	7
Other	8

**Table 4: Number of psychological conditions reported for all appointments**



### Complexity of Unmet Psychological Need

Staff completing the data sheet were asked, on the basis of the child’s presentation, to record a rating estimating what they understood was the complexity of the psychological problem they had identified. The complexity ratings were outlined on the data collection tool, and were taken from national recommendations developed by the Paediatric Psychology Network<sup>4</sup> Expert Reference Group when working on assisting in the design of appropriate dataset capture in specialist Children’s Hospitals. These ratings are now utilised in hospitals such as Great

<sup>4</sup> Division of Clinical Psychology, Faculty for Children & Young People, British Psychological Society



Ormond Street and other tertiary centres. They also inform the recommendations outlined in “What Good Looks Like”<sup>5</sup>.

The ratings are:

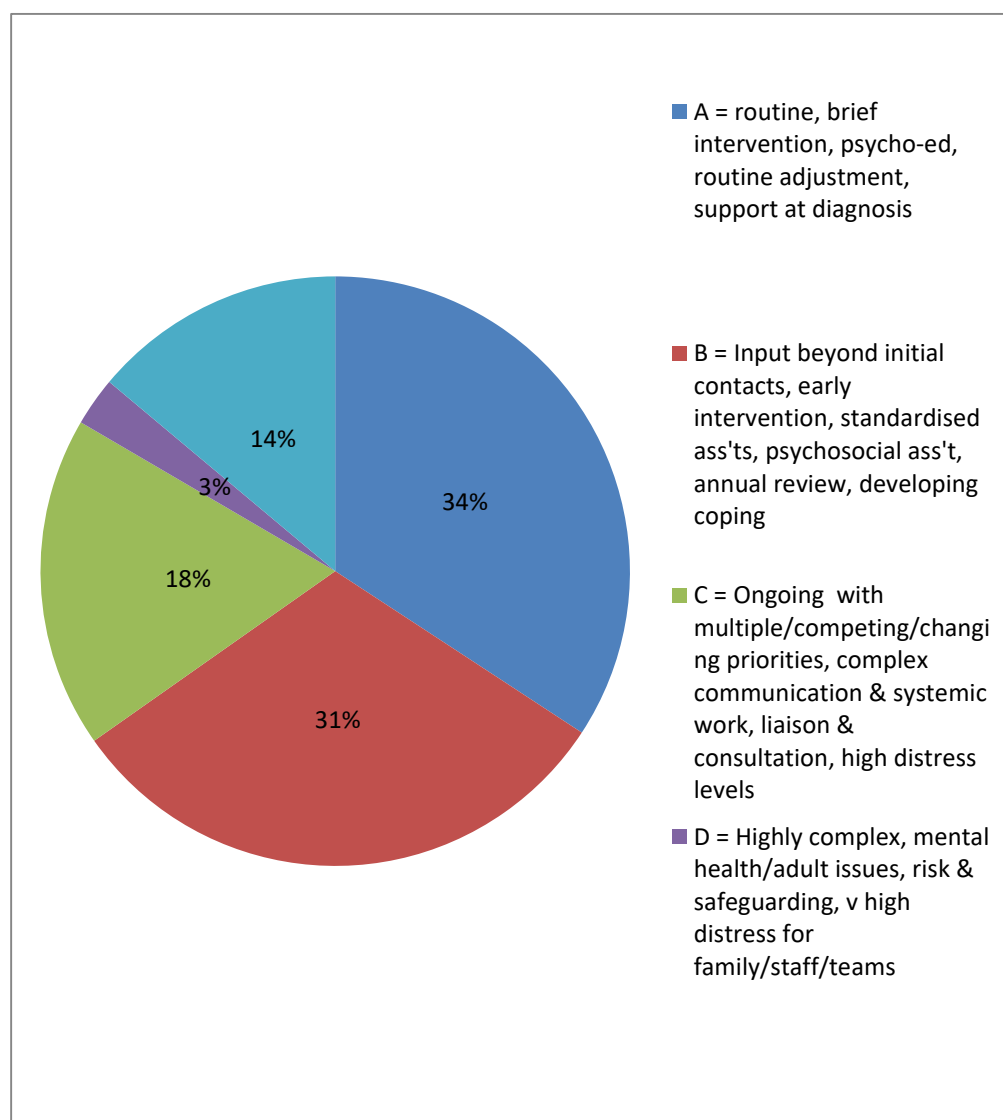
- A. Routine, low level, psycho-education, brief intervention, meeting at diagnosis, or routine adjustment
- B. More involved piece of work, input required beyond initial contacts, early intervention input (e.g. standardised assessments, psychosocial assessment, annual review) and developing coping/adjustment
- C. Ongoing work with multiple, competing and/or changing priorities, complex communication and systemic work, liaison & consultation, and high distress levels
- D. Highly complex psychological issues, mental health/adult overlap, risk assessment and safeguarding concerns, very high distress levels for family, staff and teams

Clearly the judgement of the staff completing the tool will have reflected their understanding and awareness of psychological presentations.

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<sup>5</sup> What Good Looks Like in Psychological Services for Children, Young People, and Families, Division of Clinical Psychology, BPS 2015

**Table 5: Complexity ratings of unmet psychological need: all appointments (n = 190)**



The table demonstrates the range of complexity of need across the population, with significant numbers requiring support beyond the initial routine, early intervention and preventive activity. We would anticipate that were psychological intervention to be available early on in the patient pathway, later levels of complex need may be reduced.

It is important to understand that low levels of complexity here does not indicate that lower levels of skill are required to address those problems. 'What Good Looks Like' outlines the whole-systems approach to service provision that is widely adopted within national paediatric psychology services:

*"One of the crucial over-riding principles is taking a whole-child and whole family approach, and a patient-centred approach.....A comprehensive psychological service aims to utilise expertise to enhance the quality of experience of all children, young people and their families and improve the*

*psychological competence of staff and provide governance for psychological interventions delivered by non-psychology staff. It should also educate and skill-up front line staff across agencies and along the whole patient pathway, by providing training, consultation and psycho-education.....the service cyp receive should be flexible and adaptive. “ (2016)*

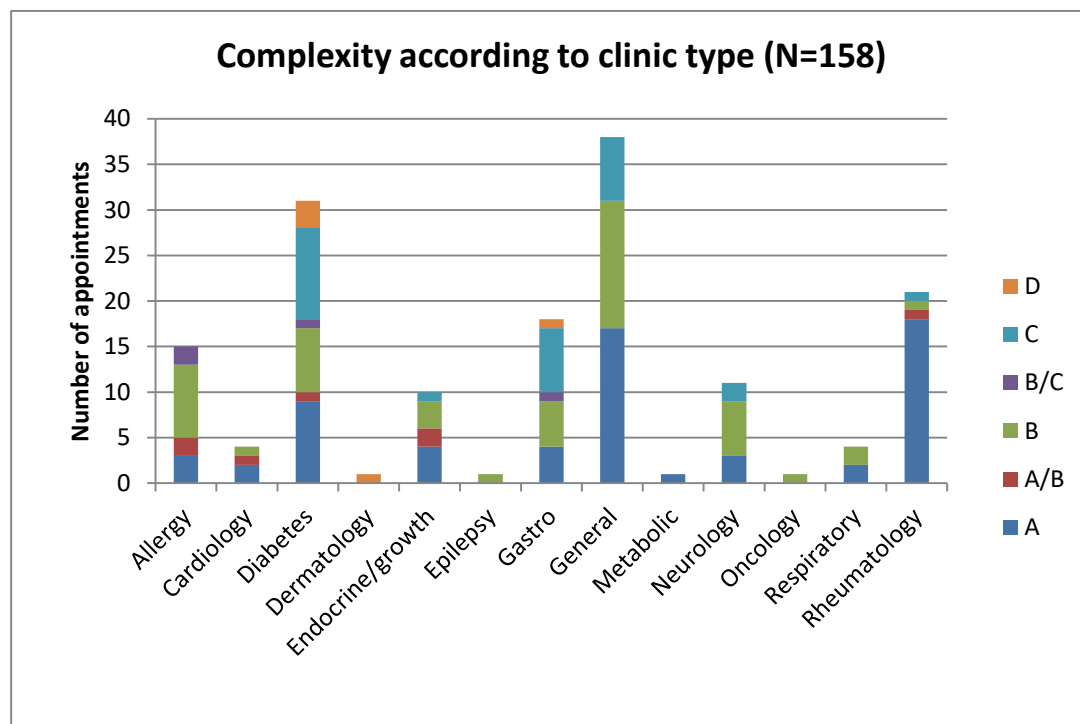
A quality and effective/efficient paediatric psychology service therefore aims to provide interventions, based on up-to-date psychological knowledge and theory and including systemic approaches and not just face-to-face contact with children and families, across the whole “windscreen” of need. Paediatric psychologists will be able to help medical staff and teams identify vulnerability including recognising when prevention activity may be indicated. It will typically assist with:

- ✓ Prevention and early support, and assist in identifying anticipated vulnerability
- ✓ Supervision and consultation of medical staff/teams
- ✓ Support psycho-social meetings and forum
- ✓ Help address staff well-being and stress
- ✓ Promote good psychological care as part of Trust policies, procedures and pathways
- ✓ Support excellent transition
- ✓ Screen for vulnerability and provide targeted help
- ✓ Provide timely and specialist help for highly complex needs
- ✓ Provide containment at times of particular anguish

We also looked at which particular clinics reported what levels of complexity and severity in the (unmet) psychological needs of children presenting there. This was to try and ascertain where the majority of needs appear to be identified, and to help identify particular clinical areas where any future psychological resource might best be placed, at least in the first instance.

Medical staff reported on the estimated level of complexity of unmet psychological need that they perceived in children presenting in clinic. At times they reported more than one level of complexity, either because they felt the complexity varied depending on the issues identified (there may have been more than one) or because they felt the estimated complexity spanned more than one category. In these cases therefore complexity estimates include where there is more than one category:

**Table 6: Complexity according to clinic type**



- A. Routine, low level, psycho-education, brief intervention, meeting at diagnosis, or routine adjustment
- B. More involved piece of work, input required beyond initial contacts, early intervention input (e.g. standardised assessments, psychosocial assessment, annual review) and developing coping/adjustment
- C. Ongoing work with multiple, competing and/or changing priorities, complex communication and systemic work, liaison & consultation, and high distress levels
- D. Highly complex psychological issues, mental health/adult overlap, risk assessment and safeguarding concerns, very high distress levels for family, staff and teams

The data shows us that:

- ✓ In **allergy** clinics the level of complexity was mainly perceived as mainly requiring a more involved piece of psychological work, with some children or young people requiring earlier intervention and some with more complex presentations
- ✓ In **cardiology** clinics the numbers of appointments for children presenting in clinic were relatively low, but the level of complexity were generally higher (i.e. greater proportion of children in cardiac clinics were perceived as having more complex need)
- ✓ In **diabetes** clinics there is a clear spread of complexity of need from routine low-level input through to cases with highly complex need and high levels of distress and

disturbance, including risk assessment needs. Given that there is already a limited psychological resource available in the MDT there are high levels of unmet need still being captured which outstrip capacity. This confirms the team's view as shared and recorded in their risk register

- ✓ In **dermatology** clinics there are low numbers of appointments for children with unmet need recorded, but of those recorded all are felt to have high levels of complexity of need. This may have been because dermatology patients are seen within general paediatrics and only the patients with more complex issues are referred for a specialist dermatology review
- ✓ In appointments for children in **endocrine** clinics the spread of complexity is fairly even but a significant proportion of the total (about 40%) have moderate to high levels of complexity of need
- ✓ In **epilepsy** clinics relatively small numbers of appointments for children were recorded but of those all indicated moderate levels of complexity. The numbers are likely to be an underestimate of the unmet need in this patient group partly due to the high intensity nature of this clinic along with a possible lack of understanding of the benefits of psychology intervention from the clinicians. The degree of complexity is a reflection of the multiple pathologies these children often have
- ✓ In **gastroenterology** clinics significant numbers of the appointments were recorded as having moderate to high levels of complex psychological need in the child or young person with proportionally fewer at lower levels of complexity requiring routine or brief intervention. The largest numbers of appointments for children with unmet psychological need here were recorded as having complexity c or above
- ✓ In **general paediatric** clinics there was an even spread of complexity recorded, but more than 50% of appointments were regarding children perceived to have a complexity of need above the requirement for routine or brief intervention (b or above)
- ✓ In **metabolic** clinics few numbers of appointments were recorded as featuring a child with unmet psychological need, and of those recorded all were felt to require routine or brief intervention or adjustment at diagnosis (i.e. early intervention and prevention activity)
- ✓ In **neurology** clinics the majority of appointments were recorded as featuring a child with higher complexity than low levels, the majority requiring input beyond early intervention
- ✓ In **oncology** clinics the unmet psychological need was recorded as moderately complex, although the level of unmet need in terms of numbers of children was relatively low. This

MDT already has integrated psychological resources and this may be a reflection that the majority, though not all, of psychological need is currently met within the team

- ✓ In **respiratory** clinics low numbers of appointments featuring a child with unmet need were recorded, although complexity of unmet need was low to moderate (a and b). Some children with a respiratory diagnosis of cystic fibrosis do have access to an integrated psychology resource via the CF MDT, which may explain the reporting here
- ✓ In **rheumatology** clinics staff reported high levels of unmet psychological need, and although the majority were felt to have lower levels of complexity a small proportion were recorded as having higher levels of complexity. This is suggestive of the need for access to early intervention and prevention activity from a psychologist

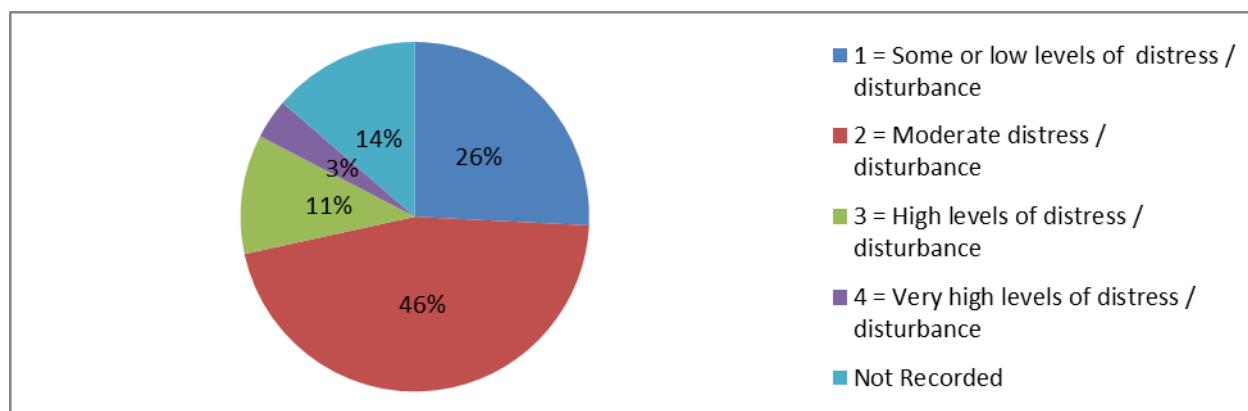
The implications of these results will be looked at in the conclusions of the report.

### Estimated severity of psychological disturbance (as above)

We also looked at the reported severity of the unmet psychological need seen in clinics. This captures information about perceived levels of psychological distress and/or disturbance, rather than the level of complexity that the case might warrant in terms of intervention.

Well over 50% of appointments featured children or young people with moderate to high levels of distress or disturbance:

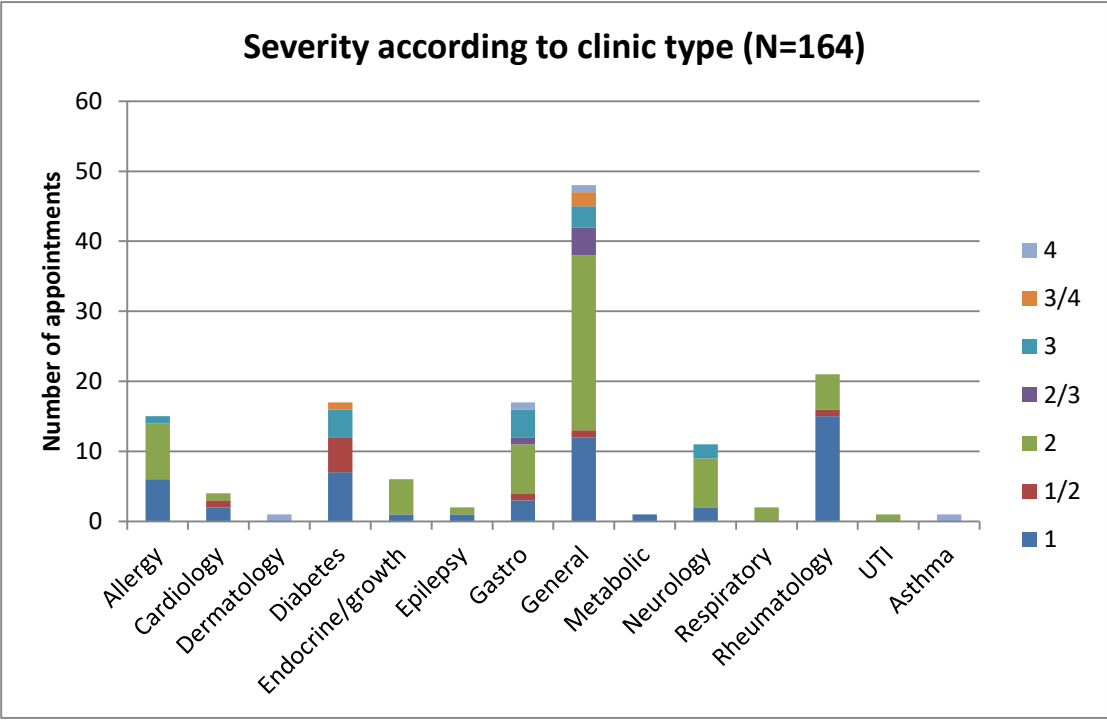
**Table 7: Severity of disturbance – all appointments (n = 190)**



We felt it was important to explore what levels of severity (of perceived or reported psychological distress) presented in different types of paediatric clinic, to help us understand

which clinics could be prioritised if psychological services were to be developed. Staff sometimes reported more than one level of severity since they reported more than one type of psychological need:

**Table 8: Severity according to clinic type**



Looking at this data, especially in the context of the data about levels of complexity of intervention required, tells us that some clinical areas or clinics report the highest levels of need in our paediatric population. The clinics most prominent are:

- ✓ Allergy
- ✓ Diabetes
- ✓ Gastro
- ✓ General paediatrics
- ✓ Neurology

To explore this further still, we looked at appointments for children with the highest levels of complexity (scores of 3 or 4) and asked which particular clinics they occurred in:

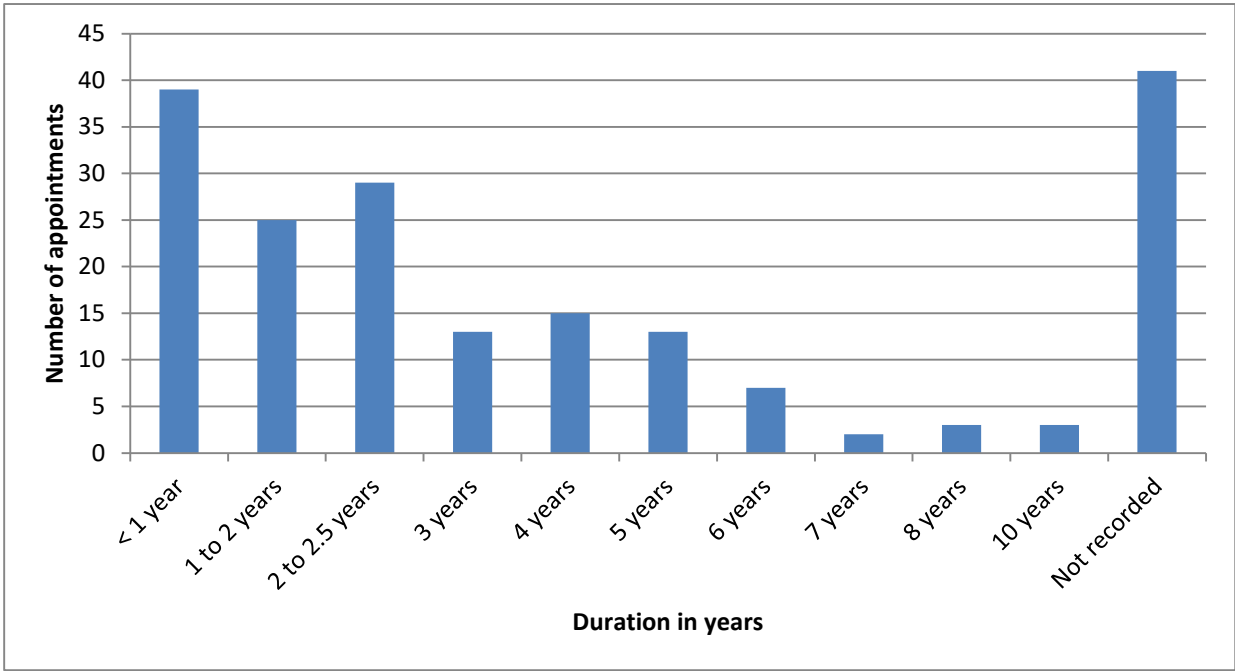
Again, this highlights that particular clinics have reported higher levels of severity of unmet psychological need, broadly in line with the reported levels of higher complexity. This has

implications for future decision-making regarding where any future increase in resource might be best placed. However, it should be noted that although it may be effective to place resource where there is the highest level of complexity/severity, this would be at the expense of engaging in the early intervention and prevention activity in other clinical areas or clinics, which has proven efficacy and is also potentially more efficient.

**Estimated duration of problem (as above)**

We wanted to know, for those appointments featuring children with reported unmet psychological need, how long the current reported (psychological) difficulties had been experienced. Therefore medical staff were asked to record the duration of the unmet psychological need they were capturing:

**Table 9: All appointments for a child with unmet need: duration of problem**



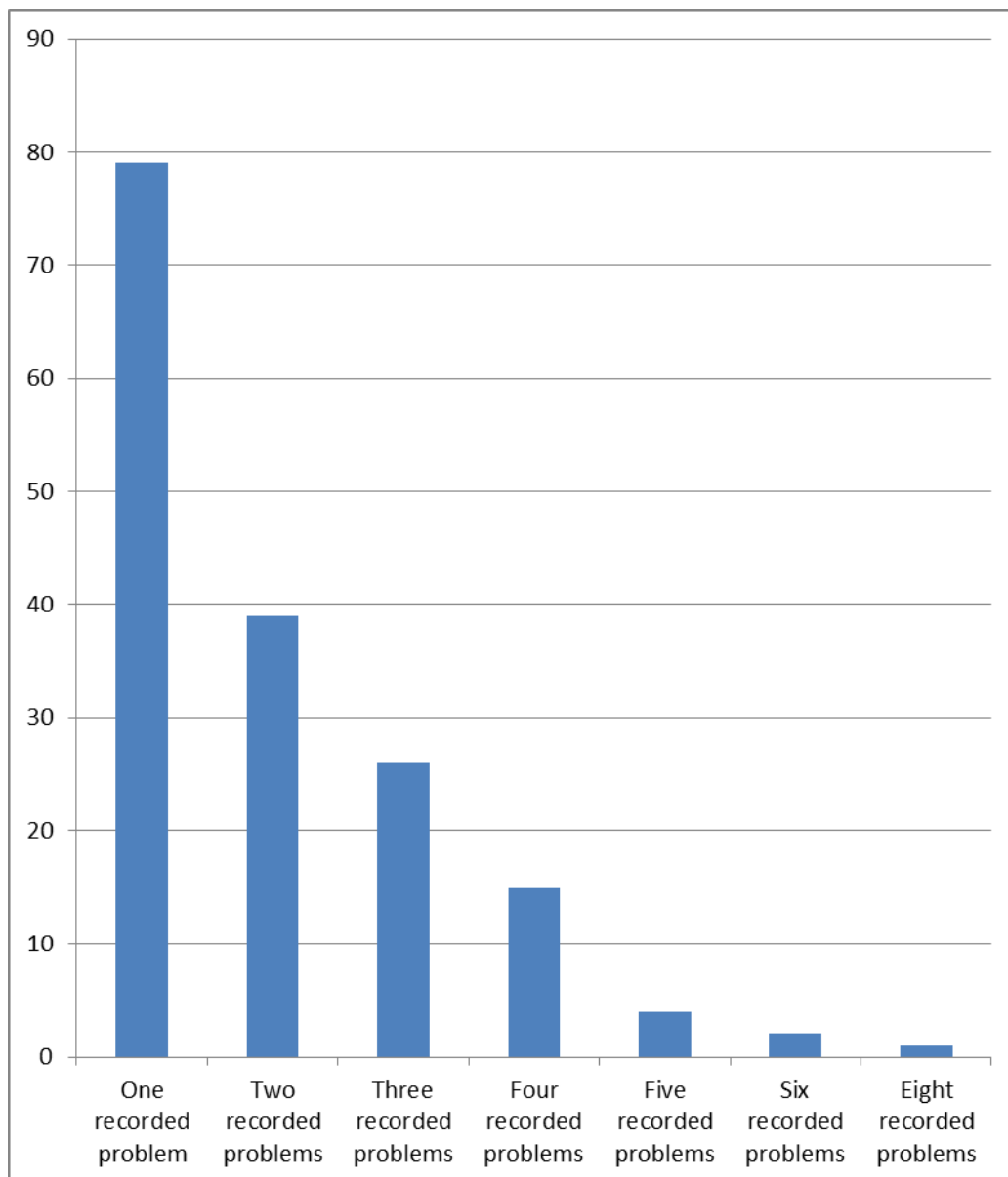
The data tells us that although there are high numbers of appointments for children whose psychological difficulty (regardless of severity of that condition and the complexity of intervention required) had been experienced for less than a year, the majority had experienced difficulties for more than that. In some cases children had experienced significant difficulty for many years.



## Numbers of appointments for children with more than one presenting problem

We also wanted to know whether children presenting with unmet psychological need had one or more identified/reported psychological problem. We therefore asked staff, using coding provided, to record what specific psychological need they were reporting on. The results indicate that in most cases staff reported one psychological problem, although a significant number were recorded as having more than one problem.

**Table 10: Number of appointments for children and number of recorded psychological problems identified by medical staff**



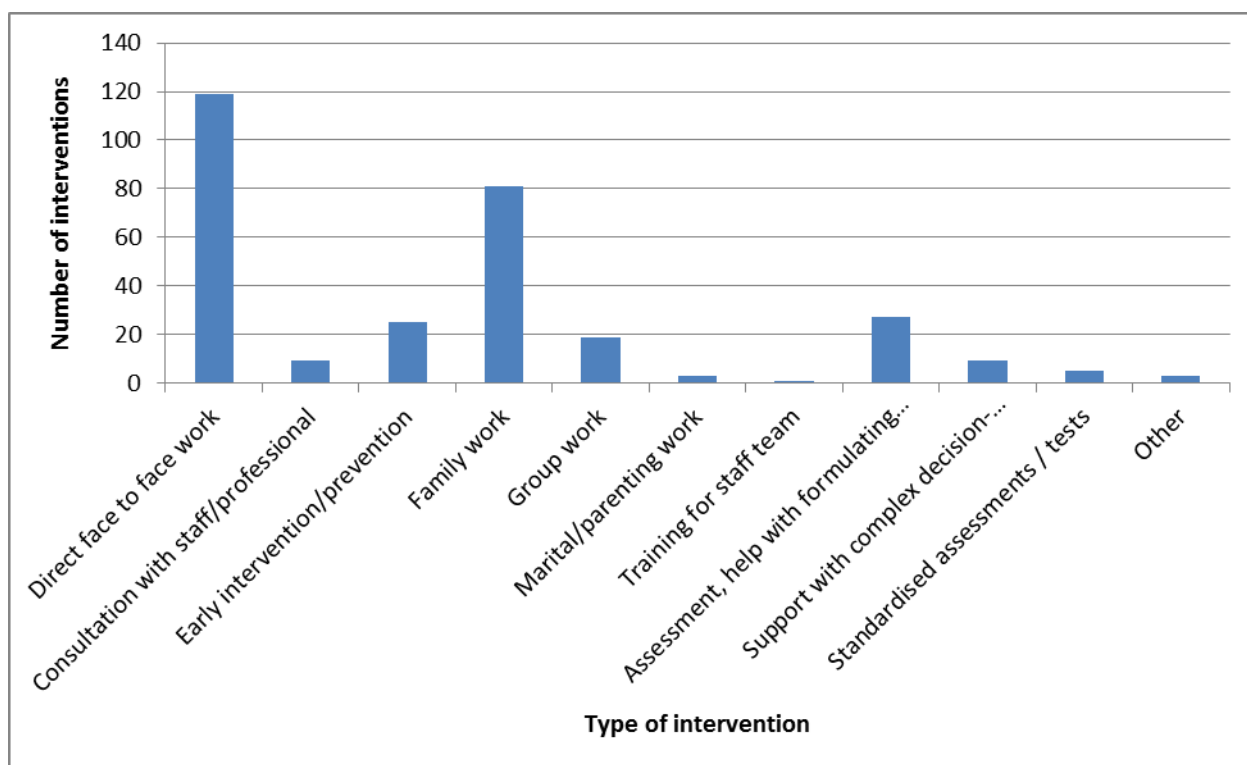
## Type of Psychological Support Required

We also asked staff to tell us, using codes provided, what type of psychological intervention they felt the child with unmet psychological need might require. This data needs to be understood in the context that some staff have not worked with a paediatric clinical psychologist and therefore may be unfamiliar with what interventions are indicated or available. Not surprisingly, many staff felt that the condition or problem they were reporting on would require direct face-to-face intervention from a psychologist, with lower numbers reporting that consultation or indirect support would be helpful. Given that this 'indirect' work, supporting staff and disseminating psychological thinking, formulation and skills, is one of the recognised and effective/efficient ways to deliver psychological care, this would indicate that staff would need time to experience this type of activity in order to understand and profit from those benefits.

### ***Types of Intervention Requested (all appointments, some >1)***

Direct face to face work by psychologist	119
Consultation for staff/professional	9
Early intervention/prevention activity	25
Family work	81
Group work	19
Marital/parenting work	3
Training for staff team	1
Assessment, help with formulating problem & care plan	27
Support with complex decision-making / MDT input	9
Standardised assessments / tests	5
Other	3

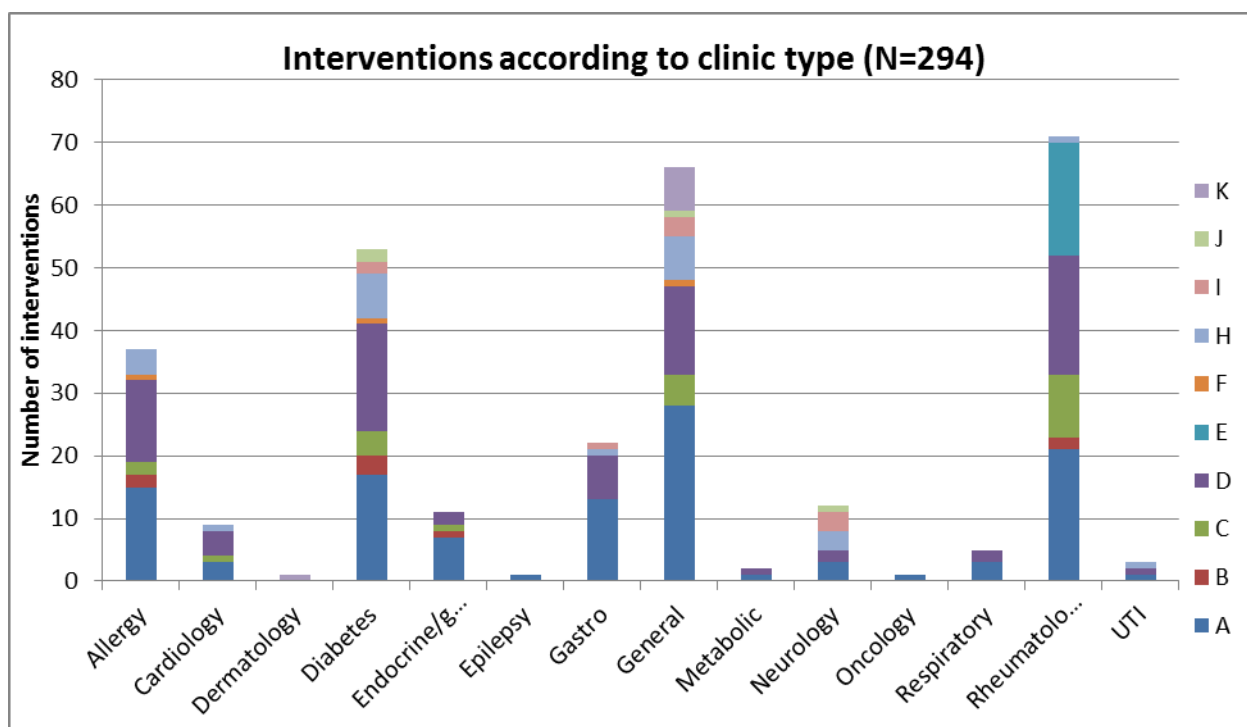
**Table 11: Type of psychological intervention required as reported by medical staff**



We also looked at what kinds of psychological interventions were felt to be required within particular clinics (more than one type of intervention may have been reported as required for each appointment/child):

- A. Direct (face to face contact)
- B. Consultation to staff / team
- C. Early intervention/prevention
- D. Family work
- E. Group work
- F. Marital / parenting work
- G. Training for staff / team
- H. Assessment / help with formulating problem and care plan
- I. Support with complex decision-making / MDT input
- J. Standardised assessments (testing / measures/screening)
- K. Other

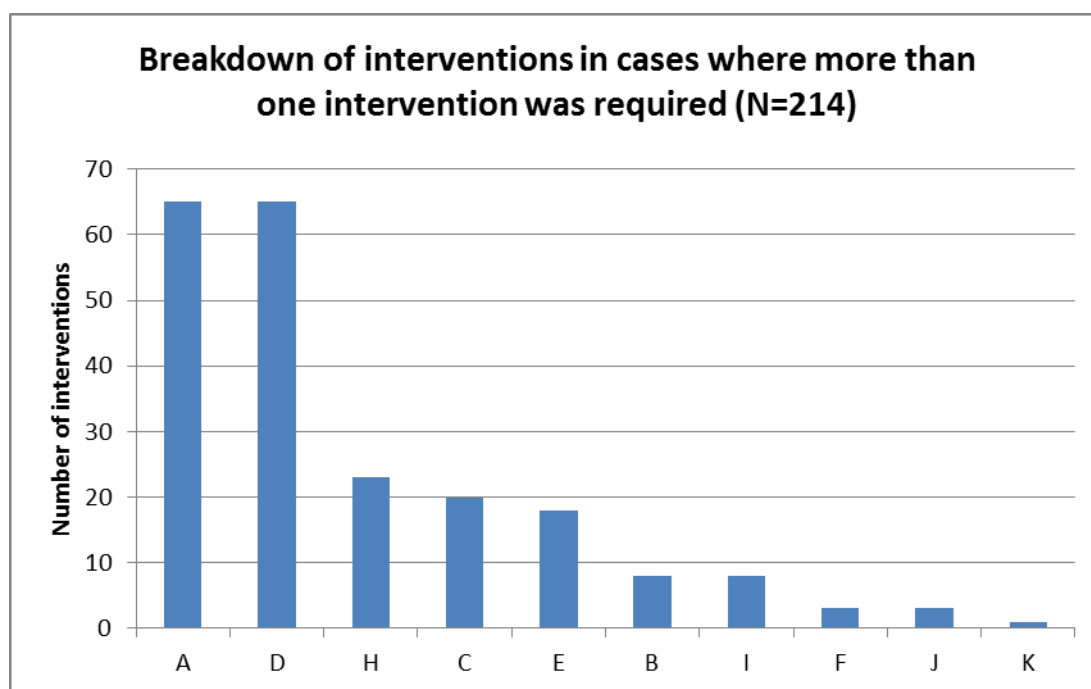
**Table 12: Interventions required according to clinic type**



We can see that most clinics reported that a range of interventions would be helpful, with significant proportions requesting more than just face-to-face direct intervention from a psychologist. Large numbers were felt to required family work and/or standardised psychological assessments or screening.

We then looked at numbers of appointments where staff had reported that more than one psychological intervention was required for the child concerned:

**Table 13: Numbers of appointments featuring children who needed more than one psychological intervention**



The data showed us that although most felt that face-to-face work with the child and family intervention was the most common combination of intervention requested, significant numbers (n=78) of appointments concerned children who were felt to require more than one intervention.

## 9. Conclusions

The audit identified that around a quarter of appointments for children and young people seen in paediatric clinics within a large district general hospital (DGH) service (operating across two hospital sites) featured a child who was recorded as having unmet psychological need and which would necessitate referral to a specialist paediatric psychology service, were one to be available. The magnitude of the unmet need within general paediatric clinics was unanticipated and highlights the need for psychological support for both acute and chronic conditions. The wide variety of clinics included demonstrates the unmet need across all groups.

Discussion with colleagues in the hospital indicate that there was not likely to be any significant seasonal variation in numbers attending out-patient clinics, with the possible exception of some in respiratory clinics (though these were low numbers relatively speaking). If further data was needed to explore and confirm this, this would need to be undertaken at a later date when discussing what the priorities are for developing psychological services and capacity.

The data collection tool used in the audit did not include any unique identifier for each child seen, and it was not practically possible for medical staff to exclude children who were seen in the audit period more than once. However, since completing the audit, data has been examined within the DGH to look at how many of the children and young people included attended more than once during the audit period. The data indicates that 87% of children (848) attending clinics were seen only once in the period Sept to Dec 2016, with 11% being seen twice (93), and only 1% attending 2-3 times (8-9). If the audit were to be repeated elsewhere it would be helpful to try and collect data using a unique identifier (such as NHS number) so that repeat attendances could be excluded. It is possible, for example, that some of the repeat attendances concerned children and young people who were required to see a member of the treating team such as in the diabetes team under Best Practice Tariff (BPT) regulations.

It is vital to note that the areas audited did not include any Community Paediatric Clinics, some clinics held for local children at the Robert Jones & Agnes Hunt hospital, or neonatology services (neonates were included in the clinics covered by the audit but would not include need generated whilst on the neonatal wards, which research suggests may be significant). There are discussions regarding running a similar audit across community paediatric clinics in the future. We would anticipate and hypothesise that similar levels of psychological need would be captured.

It is undisputed that children and young people with chronic illness and/or physical health care needs suffer significant psychological distress, as do their families. They may be described as “ordinary children facing extraordinary challenges” (Houghton 2005). Children with health conditions experience four times more psychological distress than their healthy peers (Hysing et al, 2007), which increases the risk of developing emotional, behavioural and cognitive difficulties in turn impacting on their social, emotional and educational development, and later their future occupational opportunities (Glazebrook et al 2003; Meltzer et al 2000). This vulnerability increases if the child’s brain or central nervous system is involved.

*“The long-term process of adjusting to and coping with a medical condition, managing its demands and treatment, coping with setbacks and changes in health status, and navigating complex medical systems is a challenge. Each child and young person and their family reacts differently depending on their experience of health and health care systems, personality, relationships, social and family support, cultural factors, religious and spiritual beliefs and coping styles. Other issues such as financial worries, including poverty and debt, and the demands of treatment such as medicines, procedures and special dietary needs, frequent hospital visits or admissions, involving family disruption, days off work and school, and additional child care*

*arrangements for siblings, can be an added burden.....This group of children are a diverse and often disadvantaged and stigmatised population. Their condition can interfere with their access to education and in maintaining friendships.” (What Good Looks Like 2016)*

The audit aimed to address the following issues:

**Aim 1: To identify how many children would require a service were it to be available, and their demographics**

If all the recorded unmet psychological need were to result in referral to a paediatric psychology service, we would need to assume that **around a quarter of all children seen in paediatrics within SaTH would have some level of psychological need**. This corresponds with national estimates of mental health (psychiatric) need, although the current audit looks more specifically at psychological need, including for needs which fall outside the typical “mental health” spectrum – for example issues such as difficulties with treatment adjustment and compliance. If we were to extrapolate this data, taken over a 3 month period and look at the likely annual rates, this would equate to roughly 813 children and young people who would require a referral to paediatric psychology.

It is likely that the current audit estimates are a significant under-estimate of need, since the audit did not include Community Paediatrics or neonatology, and because paediatric staff are likely to under-estimate psychological need, given their focus is necessarily to focus on physical health within the clinic.

Interestingly children with identified mental health disorders **at roughly the same levels of prevalence locally** have a relatively well-resourced multi-disciplinary mental health service which far outstrips the resources available to the paediatric population. The equivalent resource for mental health is around 50 wte staff across the same (or slightly smaller) geographical patch. The PPS currently has around 3 wte staff for the same catchment but with an additional requirement to meet with some Powys patients seen in SaTH.

It is unlikely in the current financial climate that a local paediatric psychology service would be immediately developed sufficiently to accommodate this number of children and young people, and so decisions will need to be discussed, involving both commissioners and key stakeholders, and including service users, regarding what developments should be prioritised and in what clinical areas. National evidence and recommendations should inform this discussion.

It is important to note, however, that the current audit has looked at unmet psychological need within paediatric clinics in the SaTH services. No exploration has been made within Community Paediatric clinics, nor within neonatology services, where we might anticipate similar levels of unmet psychological need.

## **Aim 2: To identify perceived need for consultation services**

Most staff felt that unmet psychological need would be best met by referring for direct face-to-face intervention by paediatric psychologists. About a quarter of appointments concerned children or presentations where staff felt that indirect consultation with a paediatric psychologist was required or would be helpful, were it to be available to them. This is perhaps not surprising given that many medical staff may feel under-skilled in psychological approaches, and have little or no access to training and consultation services to date. Nevertheless, this aspect of the existing service – the provision of space for consultation and detailed, psychologically-informed case discussion within MDTs - is seen as particularly valuable, and is also a prominent aspect of service model and delivery in the national evidence base (“What Good Looks Like” 2016). A clinical psychologist can support front-line clinicians in their own work with children, young people and their families and enable them to safely use psychological strategies for managing common difficulties. They can also support teams in formulating the child’s presenting difficulties which may not always present in straightforward ways, and help coordinate and evaluate interventions and manage risk. Psychologists help MDTs to consider a wide range of psychological, social, emotional, cognitive, developmental and systemic factors. They will help generate hypotheses to plan and test out different ways of working with a child and family, including exploring approaches when the main concern centres on the relationship itself or communication between the family and the treating team, in order to facilitate a resolution which enables the treatment to move forward more positively and collaboratively and thereby reduce the cost of ‘stuck’ treatment plans. Finally, the psychological approach can be crucial at times when complex decision-making is required, for example when risky surgery is being considered. This can take account of the child’s developmental stage and level of understanding, in the context of high levels of distress which can impact significantly on cognitive processing, and include the parents’ perspective and work alongside the medical staff. Staff also need a confidential and safe space in which to explore their thoughts and feelings formally or informally, promoting resilience and more compassionate healthcare delivery. This kind of knowledge-based skilled support can impact across the whole team.



### **Aim 3: To identify which clinical populations (based on diagnosis) require psychological input**

The results suggest that there are some clinical areas which are more prominent than others in requiring psychological input, particularly if we look at levels of complexity of intervention required. Levels of severity of presenting psychological problem suggest similar results. These areas may be considered priorities for further service development or expansion were additional psychological resources funded by commissioners. Importantly these also mirror national data. These areas – in order of highest levels of complexity of need - are:

**General paediatrics clinics:** Here staff reported an even spread of complexity of intervention required, but more than 50% of appointments were felt to concern a child whose complexity of need was above the requirement for routine or brief intervention (b or above). In the 3 month period 58 appointments for such a child were identified, which would equate to an annual projected figure of approximately 232 appointments. The children attending these appointments present with a range of medical diagnoses, which are not always be treated within an identified and organised multi-disciplinary team. This would mean the opportunities for delivering indirect consultation-based services may be reduced, for logistical reasons.

**Diabetes clinics:** Here staff reported a clear spread of complexity of need from routine low-level input through to cases with highly complex need and high levels of distress and disturbance, including risk assessment needs. Given that there is already a limited psychological resource available in the MDT (0.3 wte) the staff in the MDT are well aware what value psychology can add to the treatment available, and there are high levels of unmet need still being captured which far outstrip capacity. This confirms the team's view, and that of the PPS team, and the issue has been recorded in their respective risk registers. It also fits with the national recommendation that psychological input that is embedded within the team is a requirement. In the 3 month period an additional 30 appointments concerned patients who were identified as having unmet psychological need over and above that already available within existing resources, which would equate to an annual projected figure of approximately 120 *additional* patients with some level of need.

**Gastro clinics:** Here significant numbers of the children presenting at appointments were recorded as having moderate to high levels of complex psychological need with proportionally fewer at lower levels of complexity requiring routine or brief intervention. The largest numbers of children with unmet psychological need here were recorded as having complexity c or above. In the 3 month period 22 appointments featured patients identified as having this level of need, which would equate to an annual figure of approximately 88 patients with some level of psychological need.

**Rheumatology clinics:** Here staff reported high levels of unmet psychological need, and although the majority were felt to have lower levels of complexity a small proportion were recorded as having higher levels of complexity. This is suggestive of the need for access to early intervention and prevention activity from a paediatric psychologist. It is important to note that a small proportion of children with these diagnoses have an allocated Children's Community Nurse (CCN) locally who provide weekly injections, and this therefore enables the family (under existing PPS referral criteria) to access the current paediatric psychology service. Numbers with unmet need in the audit therefore are likely to exclude these children, and represent additional need. In the 3 month period, 20 appointments concerned additional children who were identified with unmet psychological need; this would equate to an annual projected figure of approximately 80 appointments concerning patients with psychological need.

**Allergy clinics:** Here staff recorded unmet psychological need as mainly requiring a more involved piece of psychological work, with some children and young people requiring earlier intervention and some with more complex presentations. In the 3 month period 16 appointments were identified as concerning children with unmet need – so annual extrapolations would mean that around 64 children would be likely to be referred across 12 months.

**Endocrine clinics:** Here staff reported the spread of complexity is fairly even but a significant proportion of the total appointments (about 40%) feature children who have moderate to high levels of complexity of need. In the 3 month period 12 appointments included these children, which would equate to a projected annual figure of approximately 48 children with psychological need.

**Neurology clinics:** The majority of appointments featured children who were recorded as having higher complexity than low levels, with the majority requiring input beyond early intervention. In the 3 month period 10 appointments were identified, which would equate to an annual projected figure of approximately 40 children with significant psychological need.

**Respiratory clinics:** Here low numbers of children with unmet need were recorded, with the complexity of unmet need being estimated as low to moderate (a and b). Some children with a respiratory diagnosis of cystic fibrosis do already have access to an integrated though small psychology resource via the Cystic Fibrosis MDT, which may explain the lower levels reporting here. Nevertheless in the 3 month period 4 appointments concerned a child with unmet need, which would equate to an annual estimate of approximately 16 patients with psychological need. Interestingly, recent discussions with commissioners regarding service development across paediatric medical services have focused on this group of patients, although this is not indicated by this audit as the group with the highest levels of psychological unmet need.

**Cardiology clinics:** Here low numbers of appointments concerned patients who were reported as having unmet psychological need, although we are not clear what proportion these represent

within the total numbers of children attending specialist cardiac clinics. Nevertheless, as we might expect, the level of complexity of need were generally higher. In the 3 month period 4 patient appointments concerned a child with unmet need, which would equate to an annual projected figure of approximately 16 appointments for patients with higher/significant levels of psychological need.

**Epilepsy clinics:** Relatively small numbers of appointments concerned children who were recorded as having unmet psychological need in this sample, but of those who were reported all had moderate levels of complexity of need. In the 3 month period 3 appointments featured a child or young person with unmet psychological need, which would equate to an annual estimate of approximately 12 appointments concerning a child with psychological need. The numbers are likely to be an underestimate of the unmet need in this patient group partly due to the high intensity nature of this clinic along with a possible lack of understanding of the benefits of psychology from the clinicians. The degree of complexity is a reflection of the multiple pathologies these children often have, the difficulty in achieving full control and the fear of 'status epilepticus'.

**Dermatology clinics:** Here there were low numbers of appointments for children with unmet need recorded, but of those recorded all were felt to have higher levels of complexity of need. In the 3 month period only 1 appointments concerning such a child was recorded from these specialist clinics (possibly other children were seen in general paediatric clinics). This would equate to an annual projected figure of approximately 4 patients with psychological need, albeit at higher levels of complexity. The majority of dermatology patients are often seen first within general paediatrics and therefore those seen within specific specialist clinics are likely to be those with more complex problems as demonstrated.

**Metabolic clinics:** Here few numbers of appointments were recorded as featuring a child with unmet psychological need, and of those recorded all were felt to require routine or brief intervention or adjustment at diagnosis (i.e. early intervention and prevention activity) In the 3 month period 1 case was identified, which would equate to an annual estimated figure of approximately 4 cases with psychological need.

#### **Aim 4: What level of psychological service is indicated?**

It is difficult to estimate what whole time equivalent number of psychology staff would be required to deliver the required psychological provision to certain numbers of patients, given that the range of referrals would span different levels of complexity, severity, and the types of intervention required. Some patients would need intensive input, possibly including various different forms of input, over extended periods of time, while others may be helped by offering

the treating team/staff some psychological consultation, advice and formulation. It is important to note that paediatric psychologists should engage in high levels of “indirect” (i.e. not necessarily face-to-face activity) to ensure that the service is efficient and effective (see “What Good Looks Like” 2016).

Much would also depend on the cohesiveness of the treating team and whether a paediatric psychologist could feasibly be embedded with it – it is more possible to deliver indirect intervention via staff consultation and supervision if the team is organised around the specific patient population (as is the case for MDTs such as cystic fibrosis, oncology, and diabetes). Some interventions also require more intensive and/or regular intervention and time, whilst others may only require less frequent contact with a psychologist. However, most MDTs with this kind of cohesion are specialist paediatric clinics rather than general paediatric clinics, and if paediatric psychology resource were limited to specialist clinics this would exclude large numbers of children with significant psychological need. This is an area which would need careful discussion and consideration if additional resource were to be commissioned.

Nevertheless, if we were to assume that a patient required an average of around 10 hours paediatric psychology input (the PPS data does not currently allow us to calculate average time a patient receives both direct and indirect psychology resource, so this estimate would need further exploration) then we have calculated the necessary wte staffing that this would imply. Again, it is important to note that the psychology resource available for each patient would need to include both direct (face-to-face) intervention time but also the significant time required to engage in the indirect activity such as consulting to and advising the team, whether in MDT case discussions or via teaching, training or bespoke sessions to explore a child’s psychological need.

**Using the formula above (average 10 hours per patient) and extrapolating from the 3 month audit data to cover the whole year, then the total annual number of additional children (813<sup>6</sup>) who would require referral to the PPS would indicate the need for an extra 1,500 hours, or 5.42 wte staffing (this is assuming that each member of staff worked across 40 weeks per year – or 1,500 hours).** This figure is based on the total number of children captured in the audit data who attended once, regardless of which clinic they presented in.

If we further explore what wte staffing (based on same assumptions as above) would be indicated for each specialist clinic, the following resource would be indicated: (these figures are based on the data from a breakdown of individual clinics, which includes data from repeat attenders)

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<sup>6</sup> 847 children and young people attended the clinics over 3 months. 24% (i.e. 203.5) of these were recorded as having unmet psychological need. 12 months would therefore be 813 children and young people.

Type of clinic	Annual projected number of paediatric appointments for patients with psychological need (based on extrapolated 3 month audit figures)	Approximate whole time psychology staff required (based on 10 hours per patient across 40 weeks per year)
General paediatrics clinics	232 patients	2,320 hours or 1.55wte
Diabetes clinics	120 additional per year	Additional 1200 hours or 0.8 wte
Gastro clinics	88 patients	880 hours or 0.59 wte
Rheumatology clinics	80 patients	800 hours or 0.53 wte
Allergy clinics	64 patients	640 hours or 0.43 wte
Endocrine clinics	48 patients	480 hours or 0.32 wte
Neurology clinics	40 patients	400 hours or 0.27 wte
Respiratory clinics	16 patients	160 hours or 0.11 wte
Cardiology clinics	16 patients	160 hours or 0.11 wte
Epilepsy clinics	12 patients	120 hours or 0.08 wte
Dermatology clinics	4 patients	40 hours or 0.03 wte
Metabolic clinics	4 patients	40 hours or 0.03 wte
<b>TOTAL</b>	<b>724 patients</b>	<b>4.85 wte</b>

#### **Aim 5: To identify what kind of psychological need is being identified as a service gap**

The audit data clearly demonstrated that there is a range of unmet psychological need in the local paediatric population. Medical staff have varying degrees of experience of working with paediatric psychologists and therefore we assume also have varying degrees of understanding about what kinds of psychological interventions would be helpful or indicated. Nevertheless, medical staff recorded that in their view the majority of children or young people with unmet psychological need warranted a face-to-face intervention (or at least assessment), and that a significant proportion also required some kind of family intervention.

Working in a medical setting often means seeing children and families in a much less structured way than in a mental health setting, and fitting the service provision into the existing framework of medical care (Edwards and Titman 2010). This means psychological staff need to draw on their skills across the range of complexity and severity, but also be experienced and skilled to deliver a range of therapeutic approaches and interventions depending on the need presenting at the time. The needs of children with chronic health conditions fluctuate and change over time, so that often psychologists need to develop a relationship with children and families, sometimes over many years, and help them develop resilience and independence rather than fostering long-term dependence on professional support. This is a particular skill, which is enhanced by developing a “step-up and step-down” service model.

The highest numbers of appointments concerned children who were reported as requiring help with anxiety, fear or emotional adjustment, with the next largest group needing help with managing the effects of their treatment for example with coping with side effects and/or the effects of medication. After that the most common issues were (in order):

- ✓ issues around non-compliance with treatment; family and/or sibling adjustment to the ill child’s condition or treatment;
- ✓ managing functional issues such as problems with wetting, feeding, sleeping, soiling and self-care;
- ✓ coping with procedural distress or invasive procedures; issues around identity or self-esteem;
- ✓ difficulties which might be explained as “medically unexplained symptoms”.

The remainder had difficulties with:

- ✓ parenting or marital issues;
- ✓ post-traumatic symptoms;
- ✓ anger and aggression;
- ✓ loss or bereavement;
- ✓ problems requiring neuropsychological or other highly specialised assessment;
- ✓ issues such as bullying or problems in peer relationships

A small but important proportion had problems with engagement or relationships with professionals or systems, which is generally a highly complex area to address.

As we anticipated, these do not fall neatly within typical “mental health” diagnostic categories, but are common psychological issues which have been reported frequently in national research, and highlighted in “What Good Looks Like” 2016 as typical of the paediatric population. These issues rarely fall within the referral thresholds for CAMH services, and are not appropriate for

paediatric psychology services anyway since most children are not experiencing *mental* ill-health, but the psychological consequences and sequelae of *physical* ill-health.

#### **Aim 6: To ascertain levels of complexity (of intervention) required**

The data collection tool asked staff to look at what level of complexity of psychological intervention they thought a child's presentation warranted. The results indicated that staff had an understanding of the range of complexity suggested. The coding used were taken from work done nationally addressing how to collect meaningful data from paediatric psychology services in children's hospitals, and have been adopted in various tertiary centres across the UK. The same codes are also being used by the local existing paediatric psychology service to record levels of complexity in the referred patient population.

Results indicate that around one third of paediatric appointments (34%) concerned children who require psychological intervention which is described as routine, brief or psycho-education concerning routine adjustment difficulties and/or support at diagnosis. This might be described as including much early intervention and preventative activity. Families can present with high levels of distress and shock at this point and work can be done early on in the process where possible to mitigate any longer-lasting impacts. This may include anticipating vulnerability and allowing children and families' time and opportunities to process their sometimes traumatic experiences rather than simply continue to move through the medical system without the chance of reflecting on what has happened to them. We know that this opportunity can facilitate children and their families developing better relationships with their treating teams and coping better with the demands made of them.

A further third of paediatric appointments (31%) concerned children who were reported to require input beyond those initial contacts or to need specific or targeted early intervention. This may take the form of some standardised assessments, including psychosocial assessments (these are now specified as part of best-practice and are included in peer review or other clinical audit/inspection). These also include areas of activity such as conducting annual reviews (for example in paediatric diabetes and cystic fibrosis teams) and interventions designed specifically to help develop coping skills.

Around a fifth of appointments (21%) concerned children who were felt to present with difficulties which were described as having either ongoing or multiple and/or competing/changing priorities, or highly complex difficulties including very high levels of distress and/or risk. These might include complex communication and systemic work across teams, services and agencies from secondary care and across tertiary care, and involve both families and staff displaying high levels of anxiety and distress.

### **Aim 7: To ascertain levels of psychological distress currently not being addressed**

The audit looked at levels of psychological distress not currently being addressed, by asking about (perceived) levels of severity of that distress. Again codes were given to make the data collection simple for medical staff in busy paediatric clinics.

One quarter of appointments (26%) concerned those children with unmet psychological need who were reported as showing relatively low levels of distress or disturbance. Nearly a half of these appointments (46%) concerned children who were described as having moderate levels of distress or disturbance, and a further 14% of appointments featured children who had high or very high levels of distress or disturbance. Anecdotally and from some colleagues in SaTH we know that children and families may be given little opportunity to fully express their distress in busy paediatric clinics (or may choose not to in what may not be an appropriate forum) – this is not because the medical staff there do not care, but because with limited time available inevitably the focus is primarily on dealing with the medical issues and the treatment processes. Medical staff frequently report in consultations or supervision that they are wary of “opening a can of worms” in clinics when they may not have adequate time or in some cases skills to deal with the child or family’s distress. We also know from previous audit activity within the PPS that medical staff tend to particularly under-estimate systemic and/or family disturbance but tend to focus on evident distress in the presenting child. They may also overlook or ‘misinterpret’ behavioural manifestations as not being indicative of emotional psychological distress or the impact of difficulties with family relationships, social adjustment and/or life events and trauma. Finally, they also tend to under-estimate psychological distress in babies and toddlers, which might be due to early difficulties in attachment and bonding. Therefore we assume that levels of psychological distress reported by clinic staff are likely to be a significant under-representation.

Higher levels of distress were reported in some clinics, which broadly correspond with those clinical areas identified in national research; namely in severe allergy, diabetes, gastro clinics, neurology and rheumatology clinics.

### **Aim 8: To ascertain broadly what kind of psychological intervention would be required**

Medical staff broadly reported that most children with unmet psychological need would benefit from direct face-to-face intervention. This needs to be understood in the context that many staff have not had the benefit of working with paediatric psychologists and so have limited experience of the benefits of the indirect consultation, training and supervision that could be of benefit. It is also not surprising that busy paediatric medical staff feel that working with psychological issues exceeds their capacity and skills, although we know that disseminating these skills and ways of thinking/formulating is highly effective and clinically-and cost effective. However, this kind of activity works best in established and cohesive MDTs organised around the patient group, rather than with individual and changing paediatric staff who are working in



general paediatric clinics. If further psychological resource were to be made available how this was delivered within existing medical services would need to be carefully considered.

A significant proportion also reported that some family work was warranted (we assume that family relationships were either reported as being challenging or the interactions were sufficiently troubled in clinic for this to be noted). This gives an indication that taking a systemic approach is vital; children and young people may require their own support but their families are also struggling and family/parental coping will be an important part of the treatment process and better outcomes, and medical staff are aware of this, particularly if they see the child and family over extended periods of time as treatment progresses. Children are dependent on their families' resilience and learn and model their own coping skills based on those they observe in their families. Paediatric clinical psychologists are all trained and skilled in taking a systemic approach, and the local service has also highlighted developing more formal systemic practice as an area of priority for further training.

The third largest category of intervention requested was for early intervention and prevention work. This is heartening – medical staff are well aware that intervening early can prevent more entrenched difficulties and facilitate speedier recovery and adjustment. Early intervention also has important impacts on reducing unnecessary medical contacts/tests/admissions and can have a considerable impact on reduction in costs of treatment.

It also needs to be noted that the interventions that medical staff recommended may not be the same that trained paediatric psychologists would actually deliver following assessment, since interventions would need to be based on a thorough and individual assessment of need. Currently the psychology team explore needs with children and their families at the early stages of meeting together, and frequently the focus of the intervention changes significantly from the issues raised by medical staff at the point of "referral".

Should additional psychological resource be funded and developed, it will be important to ensure that the service model retains the ability to offer interventions across the 'windscreen' of need and complexity. This ensures that early intervention and prevention are enabled; services which are based on higher or greater threshold of need run the risk of offering intervention to families too late in the process, at significant psychological and economic cost to both families and paediatric services. It also means that opportunities for offering psychological consultation and dissemination of psychological thinking and approaches across medical teams is potentially lost.

**Aim 9: To undertake a pilot in order to ascertain whether paediatricians/medical staff identify the same or similar unmet need compared to paediatric psychologists using inter-rater reliability tests**

This aspect of the audit proposal was not completed. The original proposal had included some inter-rating reliability testing to explore this issue – whether medical staff ‘correctly’ identify psychological need or presentation (both in terms of its existence and its type), and if so, whether they see that need as having the same levels of complexity as psychologists. However, it quickly became apparent that this part of the proposal would not be feasible – some medical staff work routinely with paediatric psychologists in MDTs and therefore have now developed a much greater awareness than others regarding what presenting issues might have a psychological basis, and indeed how that need might be formulated and responded to, than others. To explore this would have necessitated comparing the understanding of (sometimes complex) psychological presentations in staff who have had considerable experience of working with paediatric psychologists over several years, with the understanding of staff and/or teams who have not. This clearly would not yield comparable results. Without a psychologist in every paediatric clinic during the data collection period, it was therefore unrealistic to try and compare scores or to try and ‘validate’ whether or not identified (but unmet) psychological need was understood in the same way across medical staff. Nevertheless, given that most paediatric clinics have at least one member of staff who has routinely worked with a paediatric psychologist – albeit in another MDT setting – and there are increasing levels of awareness nationally about the impact of psychological factors within paediatrics via exposure in medical training and CPD about how psychological distress may present. We were therefore confident that levels of need would be identified with fair degrees of accuracy. Nevertheless, from anecdotal feedback locally we would assume that medical staff are more likely to under-estimate psychological need, rather than over-estimate it, and therefore the figures in the data capture are likely to be under-estimates of need.

**Aim 10: Having identified unmet need to share this data with commissioners and senior managers in order to support service development**

The audit report will be shared with local commissioners and with senior managers across both the community Trust (SCHT) and within the acute Trust (SaTH and RJA). It will also be shared with the national Paediatric Psychology Network<sup>7</sup> (PPN) and its’ membership, and may be submitted for formal publication.

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<sup>7</sup> Part of the British Psychological Society, within the Division of Clinical Psychology (DCP), and the Faculty for Children & Young People

Commissioners and Health Trusts nationally are very focused and preoccupied, currently, on children's mental health services due to the Transformation agenda. However, this may be eclipsing attention on how the paediatric population is better served specifically, to ensure that their needs are understood and met. The mental health transformation programme should of course include psychologically vulnerable youngsters with physical health conditions, but is not a priority area for discussion within the local programme.

We firmly believe that this means that the needs of this population are often overlooked or are addressed in a piece-meal or fragmented and uncoordinated way, and the voices of these children and young people and their families are not sufficiently heard or represented.

There is a national agenda to ensure that appropriate services are delivered "closer to home" – but many of our children and young people, especially those with more complex physical health conditions, only have access to any psychological support at tertiary centres given the lack of psychological provision locally. These findings also strongly support the integrated service model adopted by the existing paediatric psychology service given the identification of need across the spectrum of complexity. It also supports the assertion that psychologists work most efficiently if embedded within MDTs, so they can develop the more in-depth knowledge of the MDT and medical condition/treatment which is key to being able to offer an effective intervention.

The key challenge having undertaken this audit is to ensure that the findings are used to inform a coordinated, multi-agency cross-service discussion about the needs of children and their families and about necessary service improvements and/or developments. This needs to include the voice of the service user. To date there is no routine forum where paediatric staff and stakeholders across Trusts come together to explore their shared quality and safety agendas, reflect on performance issues, engage in horizon-scanning or work together on common challenges including the exploration of significant service gaps. The existing PPS team have developed a small but highly regarded service delivering high quality specialist and evidence-based interventions in some targeted clinical areas, and it has also been noted nationally as a DGH-level service to aspire to. The service has adopted an integrated service model which aims to deliver "seamless" and integrated care working in a collaborative way with stakeholders. However, although partnership working is well established in the context of individual children, and within the targeted MDTs, there are currently no opportunities either within the Community or Acute Trusts to meet and discuss service-wide issues, service gaps, or developments.

This is within the context of continuous service improvement strategies in paediatric services at a national level. Innovations are occurring medically, in developing appropriate and responsive

service models and delivery, and in professional groups. There is now good evidence that developing psychological services which are appropriately embedded in paediatrics can deliver significant cost savings – for example by reducing admissions and unnecessary appointments, and increasing engagement and treatment compliance. There are a number of initiatives nationally to ensure that paediatric services are standardised, and the Paediatric Psychology Network nationally are contributing to the development of national standards for service provision, and these need to be considered locally. Developments and initiatives include the development of standard service specifications, Best Practice Tariffs and funding opportunities, clinical services standards, and NICE guidance or similar evidence-based models of care; and yet there are no current local opportunities to explore or discuss, either within the Community Trust or jointly with Acute paediatric partners how these might impact on services locally. A joint Provider Forum would provide the necessary opportunities to focus on what the local offer is and how it might be improved.

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## 10. Recommendations and Action Plan

Status Key:  Red – overdue;  Amber – on track / in progress;  Green – action completed

No	Identified Issue / Area of Concern	Recommendation	Action required to implement	By Who	By When	RAG Status
1.	Engagement with all key stakeholders regarding available psychological resource and service is required including commissioners and service users	Cascade audit report to all stakeholders	Report to: <ul style="list-style-type: none"> <li>• All paediatricians and paediatric staff, and service managers</li> <li>• All Children's SDG managers for further cascade as required</li> <li>• Trust Boards – via Quality &amp; Safety committees</li> <li>• Children's Commissioners</li> <li>• RJAH and Powys stakeholders</li> <li>• Community paediatrics &amp; neonatology colleagues</li> </ul>	HG / AC	Oct 2017	
2.	Need key stakeholders to consider report in detail and identify/discuss priority areas for service development	Establish a task and finish group of key stakeholders from the relevant Trusts and	Cascade to all stakeholders Request commissioner engagement	HG / AC	Initial group to be established Dec 2017	

No	Identified Issue / Area of Concern	Recommendation	Action required to implement	By Who	By When	RAG Status
		commissioners to consider report and explore service developments  Identify criteria and weighting of key indicators to inform prioritisation	Develop service users advisory group			
3.	PPS resource insufficient to meet identified need, and is recorded on risk registers for both SaTH and SCHAT	With key stakeholders agree key areas for development, including option appraisal and areas for priority  Maintain as high priority on risk registers	Meet with SaTH representative to discuss management and identification of risks, including any mitigation options	HG / AC	Oct 2017	
4.	PPS service needs to continue to meet national and recommended service standards	Share standards with stakeholder group as part of group above (1) along with service manager review of how the current service measures against these		HG	Once group established	



No	Identified Issue / Area of Concern	Recommendation	Action required to implement	By Who	By When	RAG Status
5.	PPS resource and service delivery is not involved or included in reviews of services or MDTs with which it works and shares clinical/governance pathways	Raise with commissioners and service managers across children's services	HG to discuss with SCHAT SDG manager to ensure that service reviews include consideration of PPS resource and capacity	HG / NB	Nov 2017	
6.	There is a need to audit unmet need in RJA, Community Paediatrics and neonatology services	Cascade report to key personnel and explore options for similar audit project  Identify changes required to audit tool	Discuss with Community Paediatrics, RJA and representatives from neonates	HG	Oct-Nov 2017	
7.	Data regarding psychological need (as opposed to psychiatric need) in the paediatric population not widely available nationally	Publish report nationally and share with Paediatric Psychology Network, to enable further audit across centres and services	Co-authors to meet to develop version of report for publication nationally  Expand and explore conclusions regarding identified patient groups including risks and potential cost-savings within each specialty	HG / AC	Q1 2018	

## APPENDICES

### Appendix 1: Data collection tool for use in MDTs with no existing psychology resource

#### UNMET PSYCHOLOGICAL NEED IN PAEDIATRIC CLINICS: JOINT AUDIT

Clinic Details			
DATE	VENUE RSH PRH RJA	TYPE OF CLINIC (e.g. general paediatric, oncology, diabetes, gastro etc.)	Name of doctor(s) or staff running clinic:

1. Number (total) of patients seen in this clinic:

2. How many patients from this clinic in total **would you have referred** to a local paediatric psychology service if it had been available?

3. Sometimes it is helpful to have some case discussion with a paediatric psychologist to help inform care planning, without them actually seeing the family. For how many patients in this clinic would this have been useful?

4. Using the codes overleaf, please complete the table below for **EACH CHILD** or young person from this clinic who you feel has an unmet psychological need:

Child's initials	Child's Age	Medical Diagnosis (general) e.g.	Psychological problem – as many as apply	Complexity (of intervention)	Severity (of distress or disturbance)	Duration – how long has problem been an issue? (approx.)	What kind of support do you think would be needed? (as many as apply)


## CODES

Medical diagnosis	Psychological problem	Complexity (of intervention)	Severity (of distress or disturbance)	Duration	What kind of support do you think would be needed?
1. Gastro 2. Urology 3. Cardiac 4. Epilepsy 5. Chronic pain 6. CFS/ME 7. Rheumatology 8. Respiratory / CF 9. Endocrinology 10. Neuro-disability 11. Burns/trauma 12. Head injury 13. Stroke 14. Renal 15. Transplant 16. Disorders of sexual development	1) Non-compliance with treatment 2) Procedural distress / phobia 3) Anxiety / fear / emotional adjustment 4) Post-traumatic-distress / trauma / life events 5) Family/sibling adjustment to child's condition or treatment 6) Marital / parenting issues 7) Neuropsychological assessment / issues 8) Bereavement / loss / death & palliative 9) (Chronic) pain / fatigue 10) Managing effects of	A. Routine, low level, psycho-education, brief intervention, meeting at diagnosis, support or normalising, routine adjustment  B. More involved piece of work, input beyond initial contacts/early intervention e.g. standardised assessments, psychosocial assessment, annual review, developing coping	1. Some / low levels of distress / disturbance 2. Moderate distress / disturbance 3. High levels of distress / disturbance 4. Very high levels of distress / disturbance	Please in weeks or months	L. Direct (face to face contact) M. Consultation to staff / team N. Early intervention/prevention O. Family work P. Group work Q. Marital / parenting work R. Training for staff / team S. Assessment / help with formulating problem and care plan T. Support with complex decision-making / MDT input U. Standardised assessments (testing /

17. Cleft 18. Surgical 19. Oncology 20. Diabetes 21. Neuro-disability 22. Neuro-muscular 23. Other (please specific in writing)	treatment (side effects, medications) 11) Bullying / peer issues 12) Anger / aggression 13) Functional issues (wetting, soiling, feeding, sleeping, self-care) 14) Psychosomatic / Medically unexplained symptoms 15) Body dysmorphic / aesthetic issues e.g. cleft palate 16) Identity / self esteem 17) Engagement / relationships with professionals/systems 18) Other (please specify)	C. Ongoing work with multiple/competing/changing priorities, complex communication & systemic work, liaison & consultation, high distress levels  D. Highly complex psychological issues, mental health / adult overlap, risk assessment & safeguarding concerns, very high distress levels for family/staff/teams			measures/screening) V. Other (please specify):
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## Appendix 2: Data collection tool for use in MDTs with an existing psychology resource

### UNMET PSYCHOLOGICAL NEED IN PAEDIATRIC CLINICS: JOINT AUDIT

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**NB FOR USE IN CLINICS WITH EXISTING PSYCHOLOGY**

Clinic Details			
DATE	VENUE RSH PRH RJA	TYPE OF CLINIC (e.g. general paediatric, oncology, diabetes, gastro etc.)	Name of doctor(s) or staff running clinic:

5. Number (total) of patients seen in this clinic:

6. How many ADDITIONAL patients from this clinic in total would you have referred to the PPS other than those already being seen by them?

7. There is clear evidence that case discussion with a paediatric psychologist (rather than referral for direct intervention) is a cost effective way of using scarce psychology skills. For how many ADDITIONAL patients in this clinic would this have been useful?

Using the codes overleaf, please complete the table below for EACH CHILD or young person from this clinic who you feel has an UNMET psychological need (i.e. not currently on PPS caseload):

Child's initials	Child's Age	Medical Diagnosis (general) see codes overleaf	Psychological problem – as many as apply see codes overleaf	Complexity (of intervention) See codes overleaf	Severity (of distress or disturbance) See codes overleaf	Duration – how long has problem been an issue? (approx.)	What kind of support do you think would be needed? (as many as apply) See codes overleaf


## CODES

Medical diagnosis	Psychological problem	Complexity (of intervention)	Severity (of distress or disturbance)	Duration	What kind of support do you think would be needed?
24. Gastro 25. Urology 26. Cardiac 27. Epilepsy 28. Chronic pain 29. CFS/ME 30. Rheumatology 31. Respiratory / CF 32. Endocrinology 33. Neuro-disability 34. Burns/trauma 35. Head injury 36. Stroke 37. Renal 38. Transplant 39. Disorders of sexual development 40. Cleft 41. Surgical 42. Oncology 43. Diabetes	19) Non-compliance with treatment 20) Procedural distress / phobia 21) Anxiety / fear / emotional adjustment 22) Post-traumatic-distress / trauma / life events 23) Family/sibling adjustment to child's condition or treatment 24) Marital / parenting issues 25) Neuropsychological assessment / issues 26) Bereavement / loss / death & palliative 27) (Chronic) pain / fatigue 28) Managing effects of treatment (side effects, medications) 29) Bullying / peer issues 30) Anger / aggression	E. Routine, low level, psycho-education, brief intervention, meeting at diagnosis, support or normalising, routine adjustment  F. More involved piece of work, input beyond initial contacts/early intervention e.g. standardised assessments, psychosocial assessment, annual review, developing coping  G. Ongoing work with multiple/competing/changing priorities, complex communication & systemic	5. Some / low levels of distress / disturbance 6. Moderate distress / disturbance 7. High levels of distress / disturbance 8. Very high levels of distress / disturbance	Please in weeks or months	W. Direct (face to face contact) X. Consultation to staff / team Y. Early intervention/prevention Z. Family work AA. Group work BB. Marital / parenting work CC. Training for staff / team DD. Assessment / help with formulating problem and care plan EE. Support with complex decision-making / MDT input FF. Standardised assessments (testing / measures/screening) GG. Other (please specify):

44. Neuro-disability 45. Neuro-muscular 46. Other (please specific in writing)	31) Functional issues (wetting, soiling, feeding, sleeping, self-care) 32) Psychosomatic / Medically unexplained symptoms 33) Body dysmorphic / aesthetic issues e.g. cleft palate 34) Identity / self esteem 35) Engagement / relationships with professionals/systems 36) Other (please specify)	work, liaison & consultation, high distress levels  H. Highly complex psychological issues, mental health / adult overlap, risk assessment & safeguarding concerns, very high distress levels for family/staff/teams			
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