

Psychological Management of Children and Young People Living with HIV: Standards for Care

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All psychologists in the writing group were members of the Paediatric HIV Psychology group (PHP) and were working in posts providing services for children and families with HIV whilst writing this document. Thanks also to all other members of the PHP and others who have commented on and guided these standards over the many months and provided much needed support for the working group members.

Endorsements

This document has been endorsed by the following:

- [CHIVA \(Children's HIV Association\)](#) is the UK wide organisation for professionals and community organisations providing health, psychological and social care services for children and families living with HIV. CHIVA also has a structure for actively involving and including the views of young people living with HIV.
- [Faculty for HIV & Sexual Health \(BPS\)](#). This is one of the Faculties of the Division of Clinical Psychology at the British Psychological Society for chartered psychologists working within sexual health and HIV specialties. Members of this faculty were instrumental in developing the psychology standards for adults with HIV and we are indebted to them for supporting the need for a separate guidance for children and families and for their helpful comments on this document.
- [PPN \(Paediatric Psychology Network\)](#). This is an organisation for qualified practitioner psychologists working with children and families within paediatric health settings. The PPN is part of the Faculty for Children and Young people within the Division of Clinical Psychology at the British Psychological Society.

Foreword

This document originated from discussions during the production of *Standards for Psychological Support for Adults Living with HIV* published in November 2011 (BHIVA, 2011). Whilst there are many overlapping concerns for both children and adults, there are also specific issues for children living with HIV, particularly those with perinatal acquired HIV, which fall outside the brief of the adult standards. This document attempts to draw out issues relevant to the psychological needs of children and young people with HIV which may not be fully addressed within adult settings. This document focusses on psychology care within paediatrics which means that the majority of those being considered here are 18 years and younger and where HIV was acquired from mother to child transmission or during early childhood. However it is recognised that the recommendations are applicable up to the time when transition to adult services is complete which sometimes may not occur until the early twenties for those with perinatally acquired HIV. The following recommendations are viewed as supplementary to the adult standards and should be read alongside those when considering the needs of those adolescents both those who have grown up with HIV and also those who are acquire HIV behaviourally during teenage years.

These standards concentrate on children who have HIV infection but, where relevant, reference is also made to the needs of those uninfected children living in families where someone else has HIV (i.e. affected children). Evidence from the HIV literature is presented, where available, and where appropriate this is supplemented by evidence and knowledge from other chronic health conditions as well as from the child development literature. Children do not exist in isolation and attention needs to be given to the wider social, emotional, family and cultural factors which play a significant role in helping them to achieve their potential as well as manage their condition. Within this document

Throughout this document we regularly refer to ‘psychological support’ for children, young people and families. For the purposes of these standards psychological support is defined, as it is within the adult standards, as ‘any form of support which is aimed at helping people living with HIV to enhance their mental health and their cognitive, emotional and behavioural well-being.’ Further holistic and multidisciplinary approaches are recommended for children with chronic health needs as this is found to enhance both physical as well as emotional outcomes. (DOH 2003). Psychological support in health care is aimed at improving an individual’s adjustment to their condition taking account of changing capacity to cope with aspects of the condition and its treatment. This includes

enhancing participation in health care decisions. In a paediatric setting may also involve support focused on other members of the family, or on the family as a whole. The nature of this support and its focus will be influenced by a number of factors including the age, maturity and developmental stage of the child or young person, the wishes and cultural preferences of the family and the needs of the young person themselves.

This document aims to address some of the key issues for consideration in planning a service for children and young people living with HIV. It does not aim to specify the composition of the team or to undervalue the role that many professionals play in the psychological well-being of children living with HIV (CLWH). It does, however, aim to clarify those areas where families and young people may need referral on to more specialist practitioner psychologists who can help assess difficulties, develop a formulation which helps to describe the problem and work with the individual, the family and the team to develop a treatment plan. It aims too to help clarify and extend knowledge about where and when difficulties may arise and to guide thinking in where the gaps in our knowledge lie in order to guide future audit and research.

These standards are intended for use by all those who provide psychological care and support to children, young people and their families living with HIV as well as to those who commission services in both statutory and voluntary sectors. They are also intended as a guide to service users themselves. It recognizes that psychology provision is not currently uniform across the UK and failure to meet these key standards could adversely affect physical and mental health outcomes for children, young people and their families.

There are six standards presented as core expectations of psychology provision within Paediatric HIV. Standard 1 and 2 emphasize the need for psychology services that are accessible and appropriate for the diverse needs of a paediatric HIV population and emphasize the responsibility for promoting inclusion and participation by children and young people. Standards 3, 4 and 5 document the importance of psychological skills in supporting improving outcomes in learning, independence and emotional adjustment, in understanding and disclosing the diagnosis and in adhering to medicine and treatments. The final standard documents the importance of psychology provision and support during the transition process from child to adult health services. In each of the standards there are recommendations about monitoring and collecting data for audit and outcome research. Each standard is presented separately with an overall summary statement followed by several key recommendations. A rationale is presented for each recommendation, with implications for commissioning and auditable outcomes for each standard identified separately. References are provided at the end of each standard.

Standard 1: Access to Psychological Support

All children and young people, regardless of their HIV status, should receive care which promotes their psychological wellbeing. Children living with HIV (CLWH) should have access to psychological

services with experience of communication and adjustment in chronic childhood health conditions as well as **practitioner psychologists** who are aware of the unique needs of this client group. Psychological support should address social, emotional, cognitive and behavioural needs of the child within the context of the family and recognizing the interrelationship between health and psychological wellbeing.

Standard 2: Engagement and Participation of Children, Young People and Their Families

Services and organizations providing support for children living with HIV (CLWH) need to promote approaches which facilitate on-going engagement and appropriate participation of the child and family throughout their health and care journey. Engagement can be enhanced by **practitioner psychologists** being aware of the diverse cultural influences within this population and be able to discuss and be curious about different beliefs and attitudes relevant to health, HIV and wellbeing.

Standard 3: Identifying Developmental and Psychological Needs

Children living with HIV should have regular developmental and psychological reviews to identify any difficulties which would benefit from further assessment or intervention to help enhance the care and management of their condition. The diversity of the UK population of children with vertically acquired HIV, in terms of ethnicity, cultural origins and acculturation, indicates that care must be taken in the selection and interpretation of developmental or psychological measures standardized on non-comparable child populations.

Standard 4: Support for Knowledge, Understanding and Sharing Information about HIV

Psychological and developmentally appropriate approaches should be available to all CLWH and their carers aimed at increasing knowledge and understanding of HIV and its effects and to promote adjustment and participation in decisions about personal health care including how and when to share the diagnosis with others.

Standard 5: Psychological Approaches to Managing Treatment

Children and young people living with HIV and their families should have routine access to psychological interventions alongside medical management to support adherence to treatments. Timely access to more specialist psychological interventions should also be available, if problems arise with coping with the condition and its treatments.

Standard 6: Promotion of Psychological Wellbeing in Adolescence and During Transition between Paediatric and Adult Services

Transition of health care should be a planned process recognizing the multiple changes occurring for young people during this time and aimed at a successful engagement with an appropriate adult service. Children and Young People Living with HIV should receive care from services during transition which increase understanding and coping with their condition and enhance social, sexual, physical and emotional wellbeing. Services should be adapted to meet specific educational, social and developmental needs.

Introduction

Context

In 2011, there were 73,659 people living with HIV infection and receiving care in the UK. Only 3% of those were under the age of 24 and only 1% under the age of 15 96% of children with HIV infection were known to be infected through mother to child transmission (NAT, 2012). The Collaborative HIV Paediatric Study (CHIPS) reports approximately 1200 (under 18years) with HIV infection in UK and Ireland at the end of March 2013. Over 80% of this HIV population are of black African ethnicity, but approximately 50% were born in the UK. Most CLWH live within their biological families, usually with one or both of their parents. The last decade has seen a steady increase in the median age of the paediatric population, and now three quarters of CLWH in the UK are aged 11years or over (CHIPS 2013). Over the years there have been a small but notable number of late diagnoses of HIV in children, some of whom have arrived from other countries with unknown or complex health and psychosocial histories. This latter group can provide increased challenges to those providing care, including psychology services.

It is important to hold in mind that CLWH may not be the only children within a given family. Consideration should be given to the needs of all those children who may not themselves be HIV positive but who will be affected by the condition, either through the impact on their sibling, or via the impact on their parent or parents. The needs of children 'affected by HIV' do not form the core emphasis of these standards but should be reflected in all family-based service provision. Similarly the needs of young people approaching adulthood should be viewed in the context of their family background, their living situation and their level of independence and reference should be made to the adult standards even for those who have yet to transfer to adult services.

Why is Psychological Support Important?

Psychological support is part of holistic care and part of the role of all members of the multidisciplinary team (MDT) communicating with and caring for CLWH and their families. In this way any distress or factors which might impede medical care and treatment can be identified early and whether these relate to social, cultural, or emotional influences. Where onward referral is needed, consideration of the range of appropriate services available within the clinic or in local statutory and voluntary services is needed as well as taking account of the consent and preferences of CLWH and their families.

An understanding of child development and what is and is not developmentally appropriate at any given time is central to a clear understanding of the psychological needs of any given child or young person. Included within this should be an awareness of the wider family and changing roles and relationships at different stages in the child's life-cycle. **Practitioner psychologists** are well-placed to support the health/medical team in holding these considerations in mind.

Psychological care includes interventions for understanding and communicating about the condition, how to sustain effort to keep well, adherence to medicines, and being included as well as informed around health and care decisions. Helping the child and young person both to understand the effects of their condition but also to have some control over it and not to feel dominated by the demands it places on them, forms the basis of positive psychological wellbeing. Psychological care can also help in assessing readiness for increasing participation, independence and autonomy. Psychologists and psychological models can be instrumental in supporting these and in improving outcomes for individuals and families (Carter & McGoldrick, 2005; Edwards & Titman, 2010; Spirito & Kazak, 2006; Wallander & Varni, 1998).

HIV as Chronic Long-term Medical Condition

HIV is now defined as a chronic long-term medical condition and much can be learnt about the psychological needs of CLWH from other medical conditions including diabetes, cancer and cystic fibrosis. Whilst recognizing that differences exist between conditions, there is scope to learn from the experiences of children and families with other chronic conditions about which factors have a negative or positive influence on adjustment and outcomes as well as identifying times where extra psychological support can be particularly valuable. All chronic childhood conditions emphasize the need to provide child focused approaches delivered within a family and systemic framework. Psychology provision within paediatric settings should therefore take account of the dynamic interaction between personal, family and environmental factors and experiences on present and future outcomes.

Psychology provision has adapted as HIV has become a chronic and manageable condition to include an emphasis on future needs as well as present coping. Whilst there may still be some need for support around loss and change there is now less emphasis on coping with illness and end of life

concerns and much more on adjusting to changing life and developmental demands. These include the ordinary developmental tasks of managing school and learning, gaining independence and autonomy, navigating changing relationships with family and peers, and preparation for adulthood: including managing psychosexual and emotional changes as well as future employment and careers.

Relatively little has been documented about developmental and psychological outcomes in paediatric HIV populations in the UK. As the population is now surviving well into adulthood, the need to gather evidence of need and of effectiveness of interventions is increasingly important to plan new approaches and services and to appropriately tailor resources. The international evidence available has shown that children with perinatally acquired HIV are at greater risk than same age uninfected controls for later neurocognitive weaknesses as well as for increased levels of emotional and behavioural difficulties (Laughton et al. 2013). In the UK, 10–15% of infected children have a neurological or significant neurodevelopmental disorder and over a quarter are receiving extra learning support in school (Foster et al., 2006; Krechevsky & Melvin 2010). The level of behavioural and emotional difficulties is also noted to be increasing during adolescent years. The provision of appropriate and timely psychological interventions may help decrease the severity and impact of difficulties which may otherwise require more intense and expensive interventions later on.

Specific aspects of Paediatric HIV

HIV remains a relatively uncommon diagnosis in the UK, certainly among children, and there are a number of factors faced by CLWH which are specific to the condition, over and above a lack of knowledge faced by many other young people living with rare conditions. These include social, cultural and developmental influences.

Stigma

All those providing care to families where individual(s) are living with HIV need to consider societal attitudes and associations about the condition. Stigmatizing and negative attitudes still exist about HIV and the need for care to maintain the confidentiality of the diagnosis continues to be a paramount concern for families and providers. Whilst the number of reported adverse consequences for CLWH arising from disclosure of their diagnosis is relatively small, it may be the long-term effects arising from the burden of secrecy and fear about sharing the diagnosis with others which can result in isolation and marginalization. This in turn has consequences for children's emotional health. Accessing extra services, in social, educational and psychological care can also be limited by concerns about sharing the diagnosis.

Consequences of early exposure to HIV on developing systems

For CLWH with perinatal transmission, HIV will have been present from an early stage when other organs and systems, including the brain, were still developing. This increases the risk of later neuro-developmental, cognitive and behavioural difficulties which in turn may affect coping and progress, especially in terms of learning and school achievements. Available evidence indicates a higher incidence of such difficulties than is present in the surrounding populations: some of which may not manifest their full impact on the child's functioning until later childhood (Laughton et al., 2013).

Exposure to other influential factors early in life, whether biological or psychosocial can also affect later developmental and psychological outcomes in CLWH e.g. prematurity, early illnesses, the death of a parent, or exposure to trauma.

HIV as a family condition

Children managing any chronic health condition will be influenced by family and wider psychosocial influences. For CLWH, where HIV has been acquired through mother to child transmission there will also be at least one other person in their family i.e. the mother who also has HIV. Other family members may also have HIV e.g. father, siblings etc. This can place additional psychosocial stress on an already vulnerable system: for example inconsistencies in parenting and carers due to the physical and mental health of the mother; increased exposure to loss or illness; the presence of family secrets; or social isolation and lack of personal support because of fears of disclosure of the family diagnosis (Lwin & Melvin, 2001; Malee et al., 2011).

Uninfected (but affected) children living in households where a parent/carer has HIV will also be exposed to some of these influences, often without direct access to services which consider their emotional and psychological needs, and often without knowing about the underlying health issues in the family. These children need to be kept in mind by those providing care to carers with HIV.

Diversity in early experience

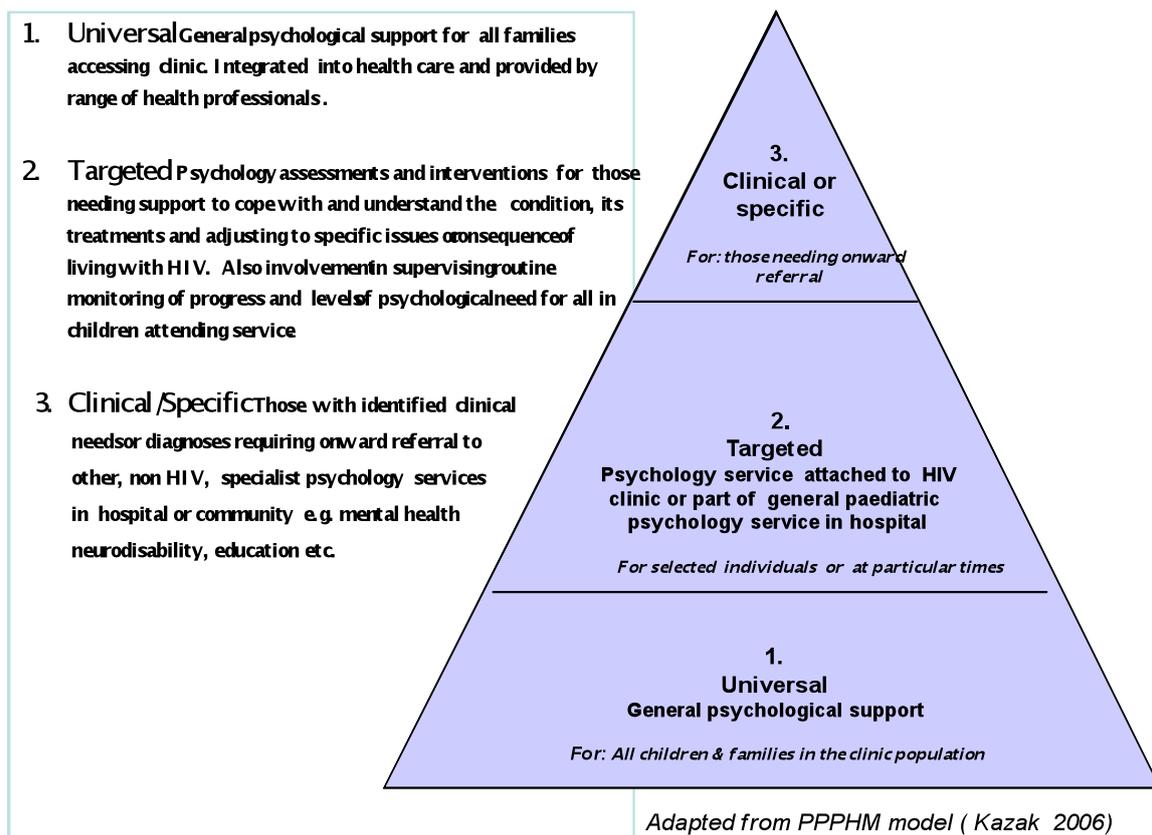
In the UK, families of CLWH come from diverse cultural and ethnic origins with many CLWH being first generation African British. There is a wide variety of differing health and spiritual beliefs within families as well as a range of different experiences of parenting and family life, health, and social care provision. Language and adjustment can influence the ease with which families and children living with HIV access care in the UK, including psychological services. This will be particularly so for older children with HIV recently arrived in the UK or diagnosed late where there maybe additional stressful experiences which will influence the speed and ease of adjustment to their diagnosis and treatments including relocation to a new country, carer and culture; learning a new language; separation from significant family members and maybe multiple losses. Some children may have been witness to or victims of earlier traumatic events such as rape.

Model of Care

It is suggested that to meet the identified needs of CLWH and the requirements of the attached standards the following service model gives the best fit and provides comprehensive and integrated psychological provision. It is adapted from a model developed in paediatric psychology services to oncology (Kazak, 2006). It is based on identifying psychological support needs for the whole clinical population but with clear ways of identifying individuals needing more targeted or specialist provision and clear referral pathways to access such provision.

Psychology service model in paediatric HIV

Psychology provision is organized at different levels with all children and young people living with HIV, their carer's and immediate family having access to a range of staff that provide general psychological support with clear links and pathways to those offering more specific or expert psychological assessments and interventions. The model integrates with the tiered approach model suggested in the adult standards.



Within this model the provision of practitioner psychology services would be placed at level 2 but with clear links and consultation to levels 1 and 3. Psychologists such as Chartered Clinical and Counselling Psychologists, with their life span training, expertise in assessment, and knowledge of a

wide range of psychological interventions for individuals, families and groups, as well as experience in consultation and research best meet the requirements of the role described.

Planning Service Provision

The historical provision of psychological services through a variety of different funding streams has resulted in diverse provision across current UK centres. In many larger services designated HIV sessions from a practitioner psychologist are integrated into the physical health multidisciplinary team. In other centres, psychology time for CLWH and families is available as part of a generic paediatric psychology service, child mental health service, or lifespan specialist HIV or health psychology service.

Appropriate delivery of care to CLWH and their family should be based on a holistic approach that takes into account developmental, social, cultural, emotional and medical factors and those specific features which separate this condition from other chronic health conditions. Psychological services integrated into medical teams is a model familiar in many paediatric health conditions and is associated with improved patient understanding and ultimately with better outcomes (DOH 2003, Nicolucci et al., 2013). In paediatric HIV, family clinics based in a MDT have also emerged as a successful model for addressing the health needs of the child and infected parents in a coordinated way. Managed and planned transition from child to adult services provides opportunities for children to gradually gain greater mastery of their condition in ways commensurate with personal factors but grounded in clear psychological theory. Practitioner psychologists can play a key role in facilitating discussions which help both team and family to hold in mind the often complex factors which might influence decisions around for example disclosure, or early sexual exploration.

As the population of CLWH in the UK gets older, continuity in provision becomes an important concern at transfer from paediatric to adult health. This can help to ensure the specific needs of those who have had HIV since birth do not get lost within larger adult HIV services. If existing provision to CLWH is part of a wider paediatric psychology service, forming links and partnerships with practitioner psychologists working in adult health or sexual health, or specialist adult HIV services will be important both pre- and post-transfer. Some centres operate a life span HIV psychology service with services to children and adults with HIV managed within one service. In this case there should be a named post holder with responsibility for the paediatric clients and with appropriate experience of child and family work. They may be a resource for their colleagues in adult services to enhance understanding of the needs of this population. Whatever the funding stream, experience and expertise in working with children and young people, and families is considered an essential core qualification.

The amount of expert psychological input to paediatric HIV clinics should be determined by a number of factors including the specific complexities and vulnerabilities of the client group. Whilst clear recommendations for levels of psychology provision per head of population are scarce there are some figures developed as guidance for children with other chronic lifelong conditions. For example

cystic fibrosis recommends 0.4wte per 50 patients. With the additional neurocognitive implications of early HIV on the developing brain and psychosexual factors, particularly the family context of the condition, a figure of 0.5 wte per 50 patients might better meet the complexity of the needs. However this guidance needs to take into account not only the needs of the population, particularly from a developmental and neurocognitive perspective, but also the skill mix and responsibilities of other team members as well as available voluntary sector support. This level of provision may vary with the age distribution of particular clinic populations, recognising that more psychology input may be required through adolescence and the transition to adult services. It will also in part be dependent on the availability of psychology within adult HIV services.

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Standard 1

Access to Psychological Support

All children and young people, regardless of their HIV status, should receive care which promotes their psychological wellbeing. Children living with HIV (CLWH) should have access to psychological services with experience of communication and adjustment in chronic childhood health conditions as well as professionals who are aware of the unique needs of this client group. Psychological support should address social, emotional, cognitive and behavioural needs of the child within the context of the family and recognizing the interrelationship between health and psychological wellbeing.

1.1. Recommendations

1.1.1. Awareness of Psychological Wellbeing

The psychological wellbeing of CLWH should be considered at each point of contact with the key professionals providing their health and social care. The needs of siblings and other family members should also be routinely considered.

1.1.2. Active Follow Up of Psychological Concerns

If key professionals have any concerns about CLWHs psychological wellbeing, these should be proactively explored. Children should be given an opportunity to talk about their concerns in a confidential and safe setting. Parents/carers and other professionals may need to be consulted, dependent on the age and competency of the CLWH. The CLWH should be involved in decisions about onward referral to more specialized psychology services where needed.

1.1.3. HIV Sensitive Care and Confidentiality

All health care professionals should be aware of the boundaries of confidentiality, but need to be mindful of the particular needs of this client group. For example, health professionals should not assume that the diagnosis can be shared universally with all other health professionals, or that an adolescent wishes to discuss sex in front of their parents or every health professional. Cultural and family health beliefs also need to be considered.

1.1.4. Appropriate Referrals

If professionals have concerns about a CLWHs and/or family member's psychological wellbeing they should make a referral to appropriate services. Depending on the issue and availability of services this could be to a generic paediatric psychology service, child and adolescent mental health services (CAMHS) or specialist HIV services. This may also involve referral for psychological support during inpatient admissions.

1.2. Rationale

1.2.1. Awareness of Psychological Wellbeing

There is increasing evidence that CLWH have increased vulnerability to psychological difficulties. For example, Melvin et al. (2007) found higher than average emotional and behavioural difficulties in CLWH, particularly during adolescent years. This was congruent with rates found in children with other chronic illnesses. Similarly Malee et al. (2011) found CLWH were at a greater risk of mental health problems than the general population.

1.2.2. Active Follow Up of Psychological Concerns

Consideration of a child's psychological wellbeing is an essential element of a comprehensive care package for all children with chronic health conditions. Standard 7 of the National Service Framework (NSF) for Children and Young People (DoH, 2003) states that services should 'consider the "whole child," not simply the illness being treated.' The National Institute of Clinical Excellence (NICE) have produced evidence based guidelines which advocate psychological assessment and intervention as key in managing a range of health conditions (NICE, 2005, 2007, 2009).

1.2.3. HIV Sensitive Care and Confidentiality

The impact of living with the stigma of HIV has been discussed in a number of books and papers worldwide (Lyon & D'Angelo, 2006; Deacon et al., 2007). CLWH and their families should be accorded appropriate care and confidentiality and this should be viewed as paramount in view of associated risks of unplanned or unwanted disclosure. See Adult standards for a more in-depth exploration of this issue (BHIVA, 2011).

1.2.4. Appropriate Referral

There is a range of evidence which shows that psychological intervention is efficacious in managing chronic health conditions (see Paediatric Psychology Network, 2008, for a review). Psychological interventions have been shown to improve outcomes for adolescents living with HIV and their parents (Rotheram-Borus et al., 2003), however few rigorous intervention studies have been conducted in this

area and there is a need for further research to ensure evidence-based practice and policy (King, Stein & Patel, 2009).

1.3. Implications for Commissioning and Planning

Services providing healthcare, social care or any other support to CLWH, should have access to an appropriate forum where they can regularly discuss the psychological needs of this client group. This should involve at least one professional with appropriate **practitioner** psychology training.

1.4. Auditable Outcomes

Potential auditable outcomes include service user satisfaction measures Service evaluation measures should be routinely used to include, numbers of referrals, primary concern, for referral to psychology , outcome of referral .

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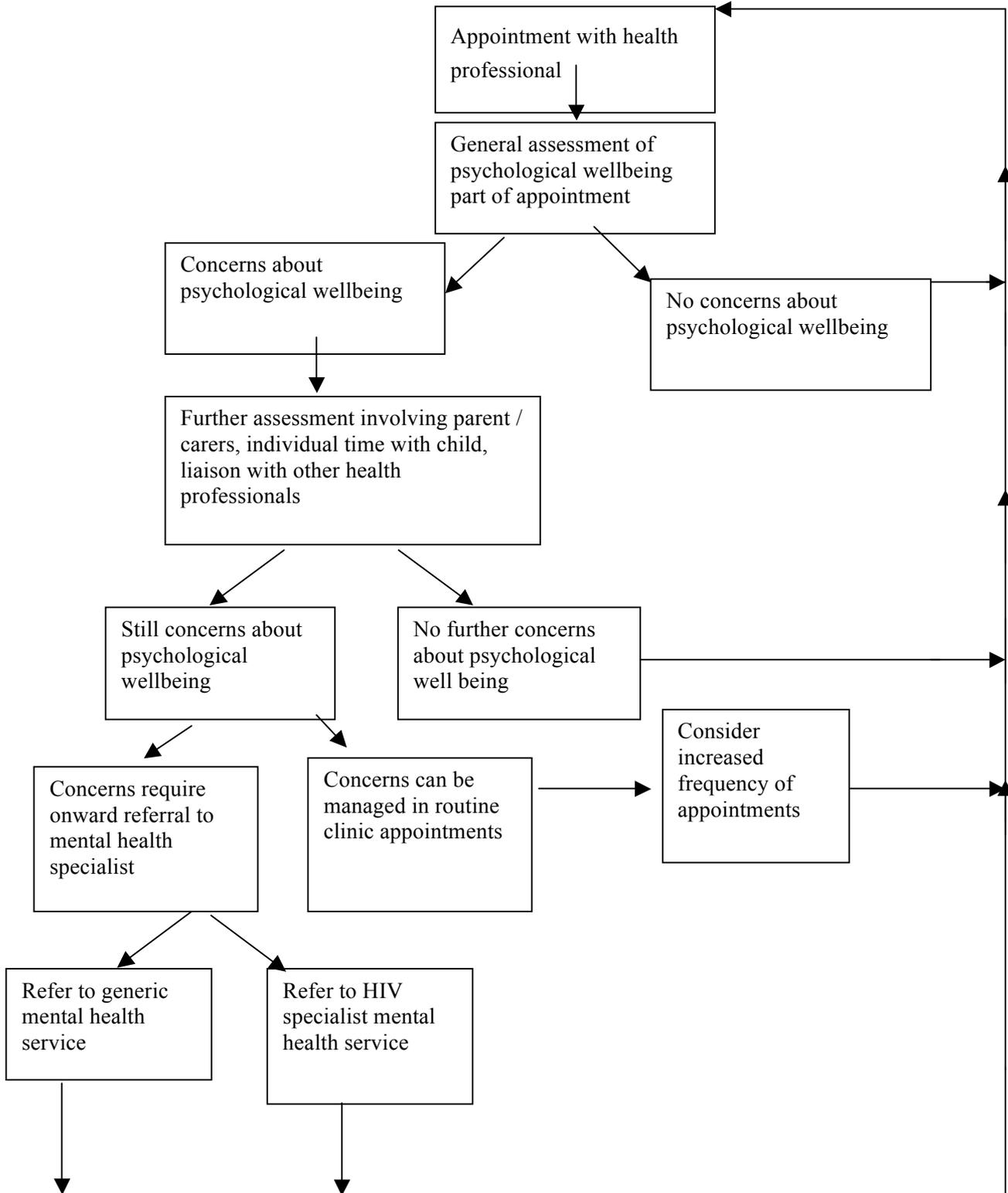
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1.6. Care Pathway



Standard 2

Engagement and Participation of Children, Young People and Their Families

Services and organizations providing support for children living with HIV (CLWH) need to promote approaches which facilitate ongoing engagement and appropriate participation of the child and family throughout their health and care journey. Engagement can be enhanced by professionals being aware of the diverse cultural influences within this population and be able to discuss and be curious about different beliefs and attitudes relevant to health, HIV and wellbeing.

2.1. Recommendations

2.1.1. Accessible and Appropriate Psychology Services

Providers of services for CLWH should proactively consider the psychological wellbeing of all those accessing their service, including others within the family who are affected by the presence of HIV. Factors such as age, gender, family support, culture, sexuality, disability and language, need to be considered when addressing psychological needs of CLWH to ensure services are accessible for all.

2.1.2. Appropriately Trained Practitioners

Some knowledge of child development, family influences, and the interaction of emotional and physical wellbeing are needed by those directly involved in the care of CLWH. Professionals providing psychological interventions should have had appropriate training and experience in engaging, communicating and involving children of different ages around sensitive issues.

2.1.3. Active Participation

Future coping and self-management of a health condition can be enhanced if inclusion and participate in discussions and decisions about care. Psychology can contribute ideas to health and social care providers about approaches which encourage involvement from children and young people, which are appropriate to their maturity and circumstances as well as suggesting ways of gaining feedback from children about effective approaches and resources.

2.2. Rationale

As well as evidence indicating that physical and psychological wellbeing are interrelated, research suggests that the quality of the relationship between practitioner and client is important in supporting children, young people and their families, particularly when they are living with a chronic conditions (Edwards & Titman, 2011). In HIV, psychological approaches are delivered by a wide variety of professionals who provide the initial support to all children and their families attending their service. In other chronic conditions these professionals can be found to have a key role not only in identifying which children and/or families need more specialist psychology services but also taking a proactive role in explaining and demystifying the onward referral; enabling the engagement to occur more successfully (Kazak, 2006). Psychologists providing services for CLWH require knowledge of child development and adjustment to chronic health conditions as well as an awareness of the specific and changing needs of this stigmatizing and family condition to engage and maintain involvement with this population (Lwin & Melvin, 2001).

2.3. Implications for Commissioning and Planning

Services should be commissioned and planned in a way that maximizes engagement, particularly in light of the complexity of needs and demands on this specific client group. This will mean considering issues such as location, opening hours, access and liaison and links with other physical and mental health services.

2.4. Auditable Outcomes

Potential auditable outcomes include monitoring rates of DNA and information about characteristics of those who access psychology services as well as those who do not. Service user satisfaction questionnaires and interviews can inform about areas of strength or areas which might be improved, as can focus groups or patient participation activities or committees.

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Standard 3

Identifying Developmental and Psychological Needs

Children living with HIV should have regular developmental and psychological reviews to identify any difficulties which would benefit from further assessment or intervention to help enhance the care and management of their condition. The diversity of the UK population of children with vertically acquired HIV, in terms of ethnicity, cultural origins and acculturation, indicates that care must be taken in the selection and interpretation of developmental or psychological measures standardized on non-comparable child populations.

3.1. Recommendations

3.1.1. Developmental Assessment

All children living with HIV (CLWH) should have a baseline clinic assessment of development within the first months of initial engagement with a paediatric HIV service. This assessment should help recognize any difficulties or delays in areas of development including movement, communication, behaviour, socio-emotional, independence and school progress which require further investigation.

3.1.2. Monitoring for Behavioural and Emotional Difficulties

Baseline assessments should also gather information and reports about temperament, coping style, current understanding of condition, and quality of life. For older children formal measures of behaviour, mood and/or emotional difficulties should be included.

3.1.3. Repeated Reviews

There should be regular updates of developmental progress and psychological wellbeing throughout childhood. It is suggested that at key developmental transition points, for example starting school, changing to secondary school, around puberty or beginning of GCSE years and transfer to adult services, could guide the timing of such follow up screening assessments.

3.1.4. Clinical Assessment

More detailed psychological assessment should also be carried out on the basis of clinical judgment where significant issues with health, education, or social circumstances emerge. This could include those CLWH who present at clinic with unusual or difficult behaviours, significant mood changes, bereavement issues, memory and learning difficulties, undue distress or anxiety over hospital visits or procedures, managing treatments and so on.

There should be a clear referral pathway to appropriate specialists or services. This may be available within the multidisciplinary Team (MDT) or hospital setting, for example paediatric psychologists, or may require onward referral to local or community specialist services for example CAMHS, educational, or specialist neuropsychology services (See 3.6 & 1.6).

3.2. Rationale

Early identification of developmental or psychological difficulties provides the best chance for interventions to be effective, particularly in promoting coping and enabling a child to best achieve his/her potential.

3.2.1. Developmental Assessment

Previous studies have indicated that children with perinatally acquired HIV are vulnerable to neurodevelopment and neurological difficulties (Willen, 2006; Foster et al., 2007). The introduction of antiretroviral treatments (ARTs) has led to significantly improved developmental outcomes and reduced acute and severe presentations such as progressive encephalopathy in children (Judd et al., 2007; Koekkoek, de Sonnevile, Wolfs, Licht & Geelen, 2008). However, there remain a core of children with demonstrable neurodevelopmental consequences, varying in severity, but evident in 10–20% in one large UK cohort. Some members of this more compromised group also have developmental delays as well as neurological consequences (Foster et al., 2007). As CLWH get older, there are increasing reports of more subtle developmental and cognitive difficulties. These underlying cognitive weaknesses commonly have attention and processing difficulties and affect learning and school progress as well as behavioural and emotional regulation (Krechevsky & Melvin, 2010; Malee et al., 2011; Scopassini, 2011; Laughton et al., 2013).

3.2.2. Monitoring for Behaviour and Emotional Difficulties

It is known that many chronic health difficulties increase the likelihood of later emotional and behavioural difficulties (Glazebrook et al., 2003; NICE, 2005). The few reports on psychological outcomes of CLWH cared for in the UK have generally reported concerns around coping and adjustment rather than evidence of significant psychological disorder (Gosling et al., 2004; Melvin et al., 2007; Sopena et al., 2010). This is particularly the case for the younger child. Adolescent years are particularly challenging for CLWH and clinical reports suggest increased levels of conduct, mood and self-harming behaviours occur during these years some of which appear to be related to underlying neurocognitive weaknesses (Lwin & Melvin, 2001; Malee et al., 2011; Laughton et al., 2013). However, there are no systematic reports available yet on the adolescent UK cohort although there is a national follow up study (Aalphi) underway. It is important to help identify those CLWH who need more psychological input as they transition into adult services.

3.2.3. Repeat Reviews

All children's development changes over time as do the challenges and protectors within their psychosocial situations. Children living with a chronic health condition need reviewing both at times of developmental transition but also when there are specific stressors likely to exacerbate coping with the health condition. Repeat screening not only picks up individual children or families who need extra support or onward referral but may identify common stressors for the group.

3.2.4. Clinical Assessment

Routine Screening for developmental and psychological difficulties on its own does not improve outcomes and must be part of a pathway or process of ongoing care, provided by staff with appropriate qualifications and expertise. This pathway needs to be responsive to changes in the individual and their circumstances to quickly identify changing patterns in clinical need. The early detection and treatment of psychological difficulties in children has been shown to improve adjustment and psychological wellbeing which in turn has implications for improved health outcomes (Every Child Matters; Glazebrook et al, 2003).

3.3. Implications for Commissioning and Planning

Routine developmental and psychological screening should be available to all CLWH and their families. A screening interview for school aged children has been developed by the Paediatric HIV psychology group and is available on the CHIVA (Children's HIV Association) website. This includes a self-report quality of life measure (Melvin et al., 2012). For younger children this screen can be used to identify those at risk of more significant difficulties and to inform at an early stage the decision to refer on for more specialist assessment.

Those aged 10 and over will require a baseline assessment to include measures of social, emotional and cognitive functioning. This assessment forms the basis of a more detailed understanding of the child's present and predicted progress and is critical to understanding the relevance of changes which may be reported during adolescence. Formal assessment should be completed by a psychologist working within HIV or paediatric services and who is qualified to administer and interpret results. This has implications for service planning to ensure adequate resources for all CLWH to enable good access to psychology service.

In some circumstances CLWH and/or other family members may require more specialist assessments or interventions. There should be a clear identified pathway for referral to those services which may differ from one locality to another.

3.4. Auditable Indicators

Routine data should be collected to include:

- Numbers in total clinic attendees who have demonstrable neurological signs/diagnosis or a neurodevelopmental diagnosis e.g. Attention Deficit and Hyperactivity Disorder (ADHD), Autistic Spectrum Disorder (ASD), dyslexia etc.
- Numbers of total clinic attendees who are assessed as having significant or specific cognitive or learning difficulty, and numbers referred on to specialist services, including child development or education services.
- Numbers reported as receiving extra support in school (and those with statement of special educational need).
- Numbers of older children presenting with anxiety and depressive symptoms, eating difficulties, self-harm or any other mental health diagnosis.
- Number referred to CAMHS, other psychological or psychiatric systems and outcome of referral.

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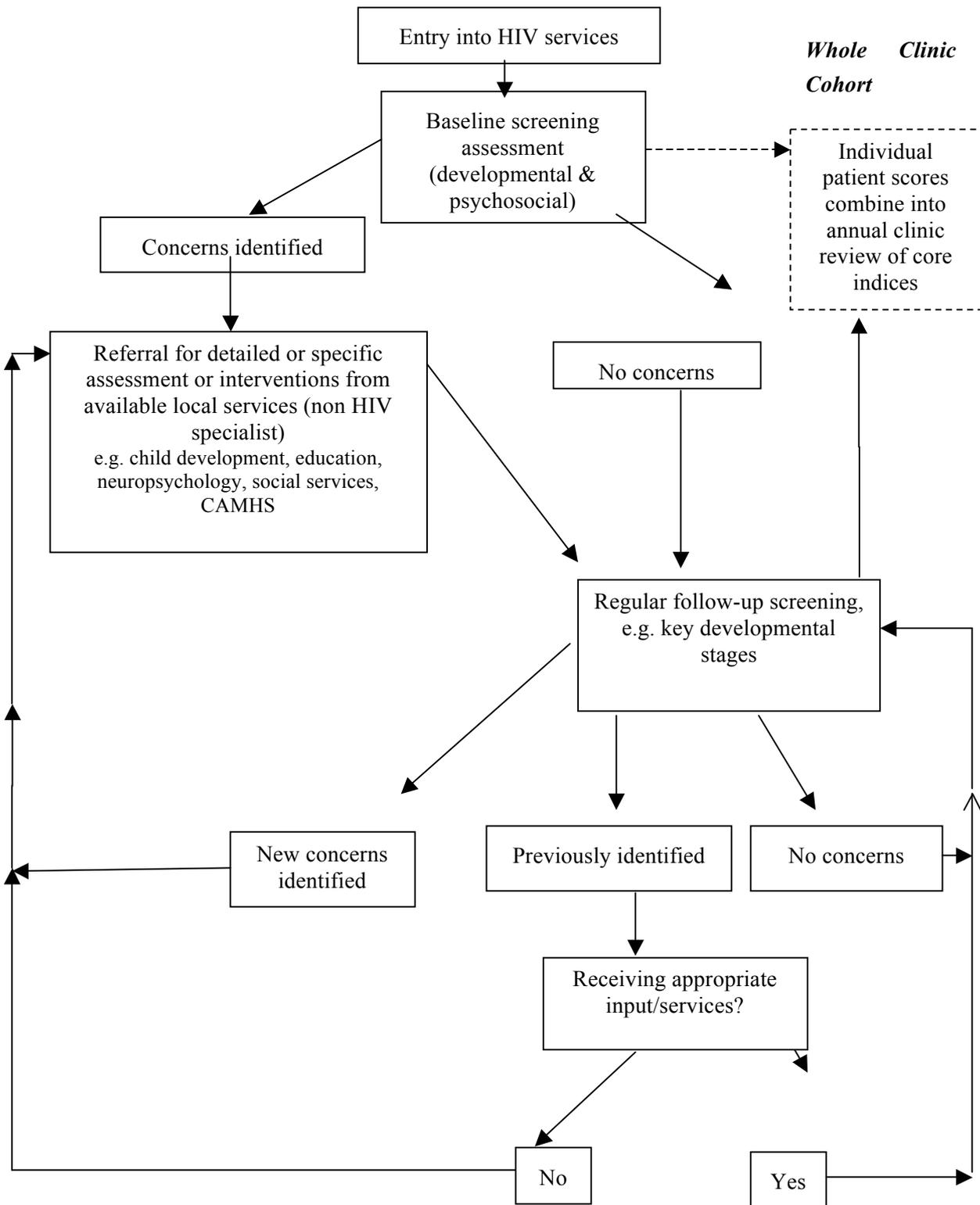
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3.6. Care Pathway

Monitoring Neurological and Developmental Progress for children with vertically acquired HIV infection

Individual



Standard 4

Support for Knowledge, Understanding and Sharing Information about HIV

Psychological and developmentally appropriate approaches should be available to all children living with HIV (CLWH) and their carers aimed at increasing knowledge and understanding of HIV and its effects and to promote adjustment and participation in decisions about personal health care including how and when to share the diagnosis with others.

4.1. Recommendations

4.1.1. Promoting Understanding and Adjustment to the Diagnosis Should Be Integrated into Health Care

Health services for children living with HIV (CLWH) should communicate about the condition and its treatments from an early age to increase children's understanding, coping and inclusion in health care and decisions and provide the foundation for future self-management of the condition.

4.1.2. Communications Should Be Developmentally Appropriate

Information, resources and interventions aimed at increasing knowledge and understanding should be developmentally appropriate and be regularly reviewed. Access to appropriate services should be available if there are difficulties with communication, comprehension or adjustment to talking about HIV.

4.1.3. Interventions Should Be Individually Tailored

There will be individual variation in the pace and content of approaches aimed at enhancing confident discussions about HIV and onward sharing with others about the diagnosis. These include temperament or personal circumstances of the child, specific family stories and experiences of HIV, and wider cultural contexts and beliefs about HIV. All these will influence readiness for disclosure. This is true both for those with HIV and those affected children who live in families where someone else has HIV.

Psychological support should take account of such individual circumstances as well as general policies around disclosure. More specific psychological interventions for the child, carer, family or for service providers should be considered if there are concerns about the emotional consequences for a child, whether they are infected or affected, arising from talking, or not, about HIV and if conflicts or difficulties within the family or care system arise from open talking about HIV.

4.1.4. Informed by Relevant Safeguarding and Legal Frameworks

Good practice in supporting HIV knowledge and onward sharing of the diagnosis should have the child's best interest and protection at its core whilst maintaining confidentiality of health information. Further all those offering support should have an awareness of legal consequences around sexual transmission and promotion of actions which reduce the risk of HIV transmission e.g. safer sex practices, maintaining viral suppression with treatment adherence .

4.2. Rationale

4.2.1. Understanding and Adjustment to HIV Should Be Integrated with Health Care

Evidence from other chronic conditions show communications based on openness between health professionals and children and their families helps promote better understanding and preparation and promotes the child's emotional adaptation and coping with their condition (Rushforth, 1999; Young et al., 2003; Ramnal, Pricor & Scott, 2012).

The World Health Organization (WHO) reviewed all the available international literature on disclosure in paediatric HIV and found many examples of both physical and psychological benefits when children are told their HIV diagnosis early with few examples of long-term harm (WHO, 2011). Some evidence of the relationship between good knowledge of the condition and later adherence to antiretroviral medicines is suggested but this relationship is complex and integrated with other influences.

In the UK, guidance for CHIVA (Children's HIV Association) suggests a partnership between health professionals and the child and carer enhances understanding and future emotional adjustment (Melvin, Donaghy & Conway, 2010; Melvin & Donaghy, 2013). This guidance also notes the importance of identifying obstacles to understanding and adjustment which require further interventions as well as recording progress in knowledge to prevent inappropriate or unplanned sharing of the diagnosis.

4.2.2. Communications Should Be Developmentally Appropriate

Children are active learners and constantly try to make sense of what is happening whatever their age. When faced with hospital illness experiences, being included in discussions in age appropriate ways helps reduce anxiety, confusion and uncertainty and enables appropriate understanding and more active coping styles (Caflin & Barbarin, 1991; Eiser, 1991; Sopena, Evangeli, Melvin & Dodge, 2010). Children are not deceived by avoidance of discussions about what is happening or the condition, whatever their age (Eiser, 1991; Ranmal, Prictor & Scott, 2012). In paediatric HIV truthful messages, even if only partial in content, has increased adjustment more than being deceived or told nothing (Funck-Bretano et al., 1997; Lesch et al., 2007; Weiner, Mellins, Marhefka & Battles, 2007). In paediatric HIV, health and social care services around the world have increasing confidence that sharing the HIV diagnosis with children at younger ages is beneficial for adjustment and allows time and opportunities to be provided for information about self-management and prevention of transmission (Donaghy et al., 2007; Weiner et al., 2007; WHO, 2011; Melvin & Donaghy, 2013).

Sharing information with children about someone else's diagnosis is more complex. There are some child reports which indicate positive emotional responses following the sharing of a parental HIV diagnosis, but less is known about appropriate timing or child factors influencing appropriate sharing of such information (New et al., 2007; Butler et al., 2009). Talking about their own HIV with their children can be a source of anxiety and worry for many parents and it may require extra psychological support or interventions (Waugh, 2003; Melvin, Donaghy & Conway, 2010).

4.2.3. Interventions Should Be Individually Tailored

There may be accompanying family stories, secrets, traumas or losses as well as child factors, such as emotional maturity, which influence the confidence and pace at which a child's diagnosis can be discussed, both to them and to others (Donaghy, 2007; Weiner et al., 2007; Melvin & Donaghy, 2013, WHO 2011). Whilst general guidance on disclosure provides a framework and ethos for services to work within, there will always be a need to take account of the readiness of individual CLWH and their specific circumstances. Further there will be some families and children who require more psychological support to enhance knowledge, understanding or communication. This is in keeping with practice from different countries. (WHO, 2011). More UK studies are needed to determine how and when to support onward disclosure to personal networks as well as to wider systems. There is some evidence from other countries of benefits if young people can share their diagnosis within appropriate friendship groups (Weiner & Lyons, 2006).

4.2.4. Informed by Relevant Safeguarding and Legal Frameworks.

Practitioners involved in supporting children's knowledge about HIV and supporting their coping with health and life activities, including sexual health, should incorporate a knowledge of relevant up to date legislation and good practice around Parental and Child Rights. This should include an

awareness of issues around capacity to consent, safeguarding, confidentiality and situations where there may be legal consequences of non-disclosure (UN Convention, 2006; Every Child Matters) and also the responsibilities and legal aspects of sexual health and transmission.

In the UK there is no legal obligation to share a child's HIV diagnosis with other agencies such as schools and other health and social care agencies but in some circumstances there can be benefits for the child if the diagnosis is shared with an appropriate member of a particular service. Sharing of a child's HIV diagnosis on a need to know basis should always be done with the knowledge of the parents/carers and reassurance that the service has appropriate confidentiality policies (Conway, 2005).

4.3. Implications for Commissioning and Planning

Psychological support for children's knowledge and adjustment to HIV may be provided by a number of different professions or services within health, social and community care. The following circumstances are likely to need a referral for more specialist psychology interventions:

- There is excessive distress from the child, carers or other family members (including other children in the family) around any discussion of HIV.
- A child has significant learning problems, communication difficulties or emotional immaturities.
- The parent has psychological, mental health or other difficulties which interfere with communicating with the child
- There are other significant psychosocial circumstances or adverse events which interfere with the child, carer or family's wellbeing including carer changes, bereavement and loss, trauma, adjusting to life in a new country etc.

Sometimes psychology services may be able to provide consultation to those supporting children within the clinic as well as taking on specific referrals.

4.4. Auditable Indicators

- Development of clinic protocols for supporting the process of telling children about their HIV diagnosis and how to support onward discussions about the diagnosis.
- Recording of reasons for any delays or obstacles to discussions e.g. communication difficulties.
- Evidence of child's coping or emotional responses to discussions about HIV.
- Interventions and resources used to enhance child's knowledge about HIV including sexual health, transmission and onward disclosure.
- Numbers requiring referral to specialist psychology services to support HIV knowledge or understanding and outcome of referral (both for CLWH and for those living in a family where parents or siblings have HIV).

- Proportion of children where the HIV diagnosis has been shared with services or individuals outside of HIV care

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4.6 Timeline for Updating Knowledge and Adjustment to HIV

Standard 5

Psychological Approaches to Managing Treatment

Children and young people living with HIV and their families should have routine access to psychological interventions alongside medical management to support adherence to treatments. Timely access to more specialist psychological interventions should also be available, if problems arise with coping with the condition and its treatments.

5.1. Recommendations

5.1.1. Promoting Understanding and Participation

Children and young people with HIV should be provided with planned, developmentally appropriate information to promote understanding and knowledge about the role of medicines in managing their health and condition. These resources are aimed at encouraging increasing participation and responsibility for decisions and management of personal health and treatments over time.

5.1.2. Cultural Considerations

Treatment support for individuals should consider cultural factors, including the role of kinship, family beliefs about medicines and religious practices such as fasting. There needs to be opportunities for an open and ongoing dialogue around different beliefs about illness and medicines.

5.1.3. Involving Others: Parents, Carers, Siblings or Mentors

Engaging family members in actively supporting a child or young person with medicine taking helps integrate adherence support into daily life. Sometimes there may be a need to identify an appropriate medicine or adherence mentor from outside the family.

5.1.4. Working in Partnership: Multidisciplinary, Multiagency and Multimodal

Appropriate professional and support networks should work in partnership together and with children, young people and their families living with HIV to promote long-term health and improve

psychological outcomes for the child. This should include age appropriate strategies aimed at supporting adherence to complex HIV treatments when needed.

5.1.5. Access to Evidence Based Specialist Psychological Interventions

Referral for more specialist interventions should be integrated into the care pathway if psychological barriers to medicine taking or adherence are identified. Such interventions should be evidenced based and tailored to meet the specific needs of individual children and families and need to be delivered by appropriately qualified psychology professionals. Psychologists have an important role in assessing underlying mental health difficulties and identifying when onward referral to non-HIV, specialist mental health services such as CAMHS is required.

5.1.6. Managing Barriers to Treatment Acceptance and Adherence

Possible barriers to treatment adherence should be assessed, documented and addressed by appropriate interventions. Interventions include medicine changes, offering social or peer support or specific psychological interventions. Occasionally child protection proceedings, involving a referral to social services, may need to be initiated, if a family is unable to protect the health and wellbeing of the child. Such proceedings may result in extra resources to enable better concordance with treatment demands.

Health providers should regularly update information about treatments and adherence in age appropriate ways and enable greater involvement in treatment decisions as the child with HIV gets older. Young people with HIV who have the capacity to make their own decisions about treatments may make different decisions to that in place at younger ages e.g. decide to take a treatment break. Health professionals need to be able to assess capacity, respect and record decisions based on informed consent and provide evidence of discussions about the legal responsibilities around onward transmission of HIV and other sexual transmittable infections (STI's) . Maintaining ongoing contact and engagement with any youngsters who decide to stop treatments will be essential both to review health and enable new treatment options to be easily available if requested in the future.

5.2. Rationale

Evidence to support the above recommendations come from a range of sources including HIV specific literature, evidence from other chronic conditions as well as from children's Rights and participation.

5.2.1. Evidence from other Chronic Health Conditions

In other chronic health conditions, many children and young people have achieved better long-term treatment adherence when psychological support was provided. A range of psychological approaches such as narrative therapy (Greenhalgh, 1999; Knight et al., 2003), motivational interviewing (Poppa et al., 2003; Rollnick, 2005), cognitive behavioural therapy (Doherty et al., 1999; Snoek et al., 1999), among others have been useful with chronic conditions such as diabetes or asthma (Bailey et al., 1990).

The World Health Organization (2003) and the National Institute of Clinical Excellence in the UK (NICE, 2009) both emphasize in their clinical guidance that:

- Patients need to be supported not blamed.
- The consequences of poor adherence are poor health outcomes and increased health care costs.
- Improving adherence might be the best investment for tackling chronic conditions effectively
- Without a system that addresses the determinants of adherence, advances in biomedical technology will fail to realize their potential to reduce the burden of chronic illness. Access to medications is necessary but insufficient in itself for the successful treatment of disease (WHO, 2003).

5.2.2. Evidence from HIV Literature

Evidence from the international HIV literature demonstrates the importance of supporting understanding and knowledge to promote long-term adherence (WHO, 2003).

In the UK evidence from BHIVA guidelines highlight adherence is an ongoing process in context of HIV and adherence support needs to be integrated into clinical practice (Poppa et al., 2003).

Evidence from clinical practice and paediatric HIV literature highlights the importance of supporting knowledge in interactive ways about how medicines help support health and prevent illness (Miah & Melvin, 2011).

5.3. Implications for Commissioning and Planning

Integrating adherence support into the clinical care pathway for children and young people with HIV will lead to better health and quality of life outcomes and more cost-effective treatments.

Children, young people and their families require access to psychological as well as practical support with adherence. Psychologists should be offering preventative work, as well as offering a range of specialist psychological interventions if difficulties arise.

5.4. Auditable Indicators

- Development of an adherence strategy or clinic protocol on adherence support for all children and young people attending a clinic.
- Proportion of children on antiretroviral treatment (ART) medicines who have seen another member of the multidisciplinary team or had extra interventions to discuss aspects of their treatment adherence.
- Proportion of children, newly starting on ART medicines, who have been referred to a psychologist for assessment and to facilitate the process of starting, maintaining and monitoring adherence over time.
- Documenting common difficulties or barriers to managing treatments or in adherence and the kind of interventions or strategies provided with clinical outcomes.

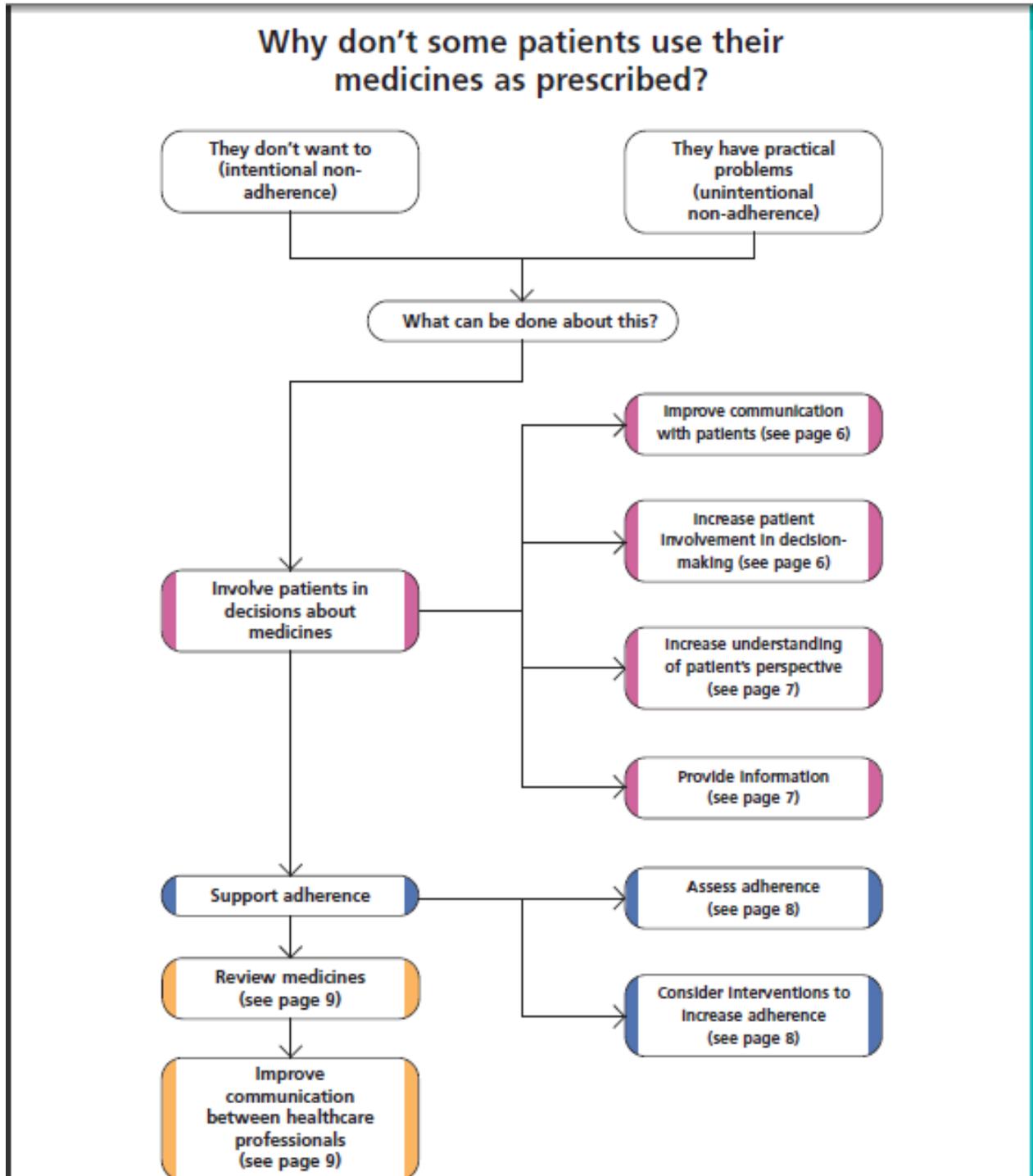
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5.6. Care Pathway

NICE Clinical Guideline 76 (January 2009), Medicines adherence: Involving patients in decisions about prescribed medicines and supporting adherence, p. 3.



Standard 6

Promotion of Psychological Wellbeing in Adolescence and During Transition between Paediatric and Adult Services

Transition of health care should be a planned process recognizing the multiple changes occurring for young people during this time and aimed at a successful engagement with an appropriate adult service. Children and Young People Living with HIV should receive care from services during transition which increase understanding and coping with their condition and enhance social, sexual, physical and emotional wellbeing. Services should be adapted to meet specific educational, social and developmental needs.

For the purposes of this standard, transition is defined as the ‘purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems’ (Blum et al., 1993 cited in National Service Framework for Children, Young People and Maternity Services: DoH, 2007).

6.1. Recommendations

6. 1.1. Planned and Supported Transition Process

Transition should take place over time in a planned and supported manner to enable young people to be prepared for and make a successful move to adult services. Transition is a continual process covering practical, medical, social and emotional areas. It is not an administrative or physical event of transfer (McDonagh, 2000).

6. 1.2. Awareness and Understanding of Changes in Adolescent Years

Understanding the interplay between typical adolescent changes and the extra demands of living with a chronic and stigmatizing health condition is essential for those providing transitional care services. Within the multidisciplinary team involved in transition services there should be practitioners familiar

with the psychological tasks of adolescence who can support the young person in developing autonomy and independent self-management of their health needs.

6.1.3. Promoting Resilience and Adjustment

As well as increasing knowledge about the condition, services should take an active role in promoting a young person's confidence, resilience and acceptance of their HIV during this time. All of these are central for autonomy, identity and the successful self-management of HIV. Building psychological resilience via the use of positive role models, peer support, websites and online forums can help young people challenge HIV related stigma and discrimination .

6.1.4. Supporting Positive Sexual Experiences and Developing Sexual Competence

Children living with HIV (CLWH) should be actively supported in their understanding of sexual development and sexual health as they progress through teenage years. This needs to be developed within the context of gender, sexuality, family context, cultural and religious beliefs Approaches and resources used need to take account of individual vulnerabilities, including learning or communication difficulties. Young people living with HIV should be encouraged to take steps towards positive sexual experiences rather than simply focusing on avoiding infection and transmission when they become sexually active.

Attention needs to be given to the confidentiality of information regarding sexual health and sexual experiences when these are discussed within a paediatric health setting and when the young person attends appointments with carers and parents.

Clear referral pathways should be in place if extra psychological support is required around coping with complex decisions about treatments, sexual health choices, understanding HIV or disclosing to peers or partners as well as for those with emotional or behavioural distress or disturbance.

6.1.5. Planning for the Future

Young people's needs in relation to planning for the future should be addressed in a way which considers his or her individual attributes, development, aspirations, choices, circumstances and concerns, and which is not centred solely around health outcomes.

6.2. Rationale

6.2.1. Planned and Supported Transition Process

National and international guidance on transition between services (e.g. DoH, 2007, 2008, 2011; RCN, 2007) and guidance specific to adolescents living with HIV (e.g. CHIVA, 2010, 2013;

Hamblin, 2011; Tenant-Flowers et al., 2011; WHO, 2011) all recommend a clear planned and structured transition process.

In HIV and other disease areas poorer clinical outcomes have been identified where the process of transition was not emphasized including poorer out-patient clinic attendance, poorer adherence to treatment and increased morbidity and mortality (Martinez et al., 2000; Prime et al., 2001; Kipps et al., 2002; Weiner et al., 2007).

There is evidence that good transition programmes can provide clinical benefits including enhanced attendance in adult care, reduced morbidity, improved patient and carer satisfaction (Boyle et al., 2001; While et al., 2004), improved follow-up (Rettig & Athreya, 1991), better disease control and improved documentation of transitional issues (Cameron, 2001; Robertson et al, 2006).

6.2.2 Awareness of Changes in Adolescent Years

Adolescence is a time of considerable physical, cognitive, social and emotional changes that can be challenging for young people and their carers. Mental health difficulties often arise for the first time in adolescence, and can include problems such as depression and anxiety, alcohol and drug use, eating disorders and self-harming (Nice, 2005). Other mental health difficulties such as psychosis may also be more likely to show themselves at this time. In addition young people living with a chronic health condition may be more at risk of developing mental health difficulties during adolescence such as depression and anxiety (Frize, 2011).

6.2.3. Promoting Resilience and Adjustment

Whilst there has been a lot of research with children and young people who have other chronic illnesses, less is known about the relationship between adjustment and coping with HIV positive young people. There are a number of measures and tools to enhance resilience which can be of use with this population (see Daniel & Wassell, 2002).

6.2.4. Supporting Positive Sexual Experiences and Developing Sexual Competence

Young people living with HIV are affected by the same pressures and social expectations as those who are HIV negative or untested, with the added burden of secrecy, shame and concerns around responsibility, perhaps especially in the light of recent cases of criminalization of HIV transmission (Tenant-Flowers, 2011, p. 14). The age group most likely to contract a Sexually Transmitted Infection (STI) is 16–24-year-olds, and the UK has the highest rate of teenage pregnancies in Western Europe (Health Protection Authority, 2008). A study by NASTSAL II found that more than a quarter of 16–19-year-olds had their first sexual encounter under the age of 16, and at this time did not meet the authors' definition of 'sexually competent.' This definition includes the 'absence of regret, autonomy of decision and the adequate use of contraception' (Wellings et al., 2001).

6.2.5. Looking to the Future

Government guidance is clear on the need for transition planning to address young people's futures and explore their choices beyond health: 'Young people with additional, and sometimes complex, needs [...] need high quality, multiagency support allowing them to have choice and control over life decisions and, in particular, to maximise education, training and employment and leisure opportunities with a view to living independently' (DoH, 2004).

The Department of Health's *Quality criteria for young people friendly health services* expects that a service 'invites and encourages all clients to give their opinions of the service offered and whether it met their needs; these are reviewed and acted on as appropriate' (DH, 2011). The Royal College of Nursing believes that 'involving young adults in developing services is vital to engaging them with the service and with their own treatment' (RCN, 2007). These principles are also relevant to social care and voluntary sector services.

Findings from consultations with young people with HIV indicate that many have ambivalent or mixed feelings about their future and some anxiety about engagement with adult services (Campbell et al., 2010; Hamblin, 2011; Hogwood et al., 2012).

6.3. Implications for Commissioning and Planning

All services should have a clearly defined and documented model of transition which integrates psychological wellbeing into physical and sexual health care provision.

Each CLWH should have an individual transition plan developed during early adolescence which is completed collaboratively with the young person, their carer and an identified transition worker within the health team. Before transfer there should be a discharge report from the paediatric clinic which documents relevant health and psychosocial history and which has been shared with young person.

This plan should include graded steps aimed at increasing understanding of HIV, promote sexual health knowledge and STI's, increase participation in health care treatments and decisions and also support independence and access to other sources of support outside the family.

When faced with health care, treatment or other decisions affecting their safety and wellbeing, adolescents should be assessed for their capacity to make independent choices and appropriate support provided if difficulties are identified. Young people should be afforded the same rights to confidentiality as adults (Tenant-Flowers, 2011, pp. 11–12).

The health team should regularly screen young people for psychological difficulties including risk of harm from self and others and be aware of the referral pathway to appropriate psychology

services and evidence based psychological treatments when needed (NICE, 2005). Screening for other factors which may affect HIV care and treatments e.g. substance use should also be built into regular clinic appointments and interventions/links with other appropriate services made accordingly.

Clinics should have systems in place to gather the views of young people using their services regarding the organization of clinics and their satisfaction with services provided. One example of this might be the use of Patient Representatives.

6.4. Auditable Outcomes

- Availability of an information sheet/leaflet for young people, and their carers, documenting the process of transition to adult services and young people's participation in this.
- Numbers of young people with a transition plan in paediatric clinics.
- Clinic DNA rates, before and after transfer.
- Numbers referred for extra psychological support both before and after transfer and reason and outcome of referral.
- Results of screening for presence of psychological difficulties and outcomes of interventions
- Interventions to support safe onward disclosure (when, how and to who) and any noted consequences.
- Resources used for sex education and for promoting safer sex
- Outcomes of screening for STIs.

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6.6. Resources

A version of the Health Passport can be accessed online at SickKids:Good 2 Go Transition Program – My Health Passport: <https://www.sickkids.ca/myhealthpassport/FormPassport.aspx?FormId=61>.

A number of HYPnet clinic proformas for use with young people can be found at: www.hypnet.org.uk/resources.html.

Examples in other health conditions:

- Nottingham transition document
- Newham transition document (to be clarified re origin of this document)

6.7. Care Pathway

A standard ‘care pathway’ for psychology services during transition of young people with HIV from paediatric to adult services is difficult to produce as the structure and availability of psychology services varies across centres.

The following summarize the basic principles and good practice for enhancing psychological wellbeing and coping during transitional care:

- Local paediatric and adult HIV services should have an agreed protocol or pathway outlining how psychological as well as health needs of young people with HIV are addressed during transition.
- Protocols should include graded steps involved in supporting increasing independence as well as preparation and transition to adult services.
- If possible there should be a transition key worker, who may come from a number of professional groups, including psychology.
- User involvement is central to the success of the transition process.
- Individual transition plans should be reviewed at least annually and include a screening of psychological wellbeing.
- A discharge summary should be completed before transfer and be discussed with the young person and should include a brief overview of key psychosocial and developmental circumstances as well as health and treatment data. Ideally this should include a young-person led document, e.g. a 'transition passport' which reflects the young person's expectation and needs from the new service.
- Acknowledging the pace of progress through transition and formal transfer to adult services will vary for individuals.
- Attending to the process of saying goodbye to paediatric staff – for the young person and parents/carers.

Psychological conversations during transition should cover:

- Progress made in sex education and sexual health information including an understanding of condom use, post-exposure prophylaxis, etc.
- Knowledge of HIV and sharing of the diagnosis: who has been disclosed to, how the young person feels about this, who they feel they can talk to.
- Psychological wellbeing: Self-assessment of psychological wellbeing and strategies for addressing or maintaining this.
- Communication: Self-assessment about confidence in communicating with health professionals, and identification of any strategies to support this.
- Attendance: Assist regular attendance by discussing potential barriers and solutions with the young person, and have a documented plan regarding non-attendance.
- Accessing appropriate support networks – peer groups etc.
- Management of own health and treatments – discussion of obstacles to good medicine adherence and access to appropriate interventions if needed e.g. motivational approaches.

By the time of transfer:

- The young person should be confident in consultations by themselves and be able to ask about their concerns and demonstrate understanding and autonomy in managing their appointments, medicine taking etc.

- Young person has had opportunities for conversations about readiness for transfer with knowledge about the differences between paediatric and adult service.
- Assessments of capacity will have been considered.
- The young person has visited the adult service/ward or met staff who work in the clinic. Where possible they have been offered the chance of talking with another young person who has already transitioned.
- The young person will have had a chance to go through their discharge summary with the appropriate paediatric professional (this should include a brief overview of past progress and future aspirations and major psychosocial factors as well as health and treatment history).