

ROYAL PHARMACEUTICAL SOCIETY

The Royal Pharmaceutical Society (RPS) is pleased to have the opportunity to share some views to support the review into the care delivered when young people transition from child to adult health services. As the professional body for pharmacists, we represent pharmacists across Great Britain and we listen to the views and concerns of our membership.

As medicines are often a central issue when care is transferred from paediatric to adult services, it is important that medication information is included in the young person's treatment plan and clearly documented in the patient's record. This information should be made accessible to all appropriate professionals when patients are treated by paediatric services and when they transition to adult services. RPS fully recommends therefore that medication management, monitoring and review must be a key component in planning arrangements to facilitate successful transfers of care.

Early planning for transitions of care from paediatric to adult services is critical to its success. We believe that a person-centred approach is vital in all transitions, with care packages tailored to the specific needs of the individual and agreed in consultation with the individual, their family and/or carers. Such early planning must also include a focus on medicines and the advice of a pharmacist, particularly for complex cases where polypharmacy is a key feature of care. A useful reference for achieving patient centred care and in particular ensuring young patients can be supported and have a genuine say in their care is the Ready Steady Go resource developed by Southampton's Children's Hospital:

<http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx>. We are supportive of this approach and would recommend it in planning arrangements for transfers of care.

We recommend that a **medicines section** should be incorporated into a 'Medical Passport' that moves with the individual between services. Ideally this should be digital and handheld, ensuring access to real time data/information for individual patients, their carers and professionals. A section on medicines in the 'Medical Passport' could also provide a good opportunity for meaningful consultation with patients/parent/carers about what they would like to know about their medicines. Ensuring that a pharmacist is included in discussions to provide expert advice on medicines management should be part of this.

The use of **un-licensed or 'off-label' medicines** is often critical in the treatment of young people. These are medicines that may not be licensed for use in children or for particular conditions but add value to their treatment plan. From a patient safety perspective, it is imperative that patients who are prescribed un-licensed medicines are supported by regular monitoring of their medicines. It is also important that local shared care protocols are put in place for the ongoing monitoring of unlicensed medicines for young people and when they transfer into adult services. We believe this must be supported by the expertise of the pharmacist as part of a multidisciplinary team approach to care

Placing a greater emphasis on **self-management** is also important in transfers of care. It is important that young people understand how and when to take their medicines to ensure they can benefit from them. Young people should also be empowered to take greater control over their medication by learning more about self-management, setting up medication reminders/alerts etc. Pharmacy teams must play an important role in this as part of multidisciplinary approaches to care.

Support for **self-management** of the young person's condition(s) should start at the earliest possible opportunity. This should include support and advice of taking medicines as well as other aspects of managing the person's health and wellbeing. A bio-psychosocial model of care is important to instil self-management values and understanding in every younger individual. This approach can help to empower young people to manage their condition and provide the foundations for their transition into adult services. Anecdotally we are aware that it can improve levels of confidence among young people and help to reduce levels of dependency on services, parents and other carers as the young person comes of age and transitions into adult care services.

Digital solutions are needed to ensure the appropriate transfer of information between professionals, and between professionals and young people. Young people will naturally engage with digital solutions and it is recommended that the guidance steers the NHS to the development of digital solutions i.e. a digital transition passport and plan. We are aware of some developments where an App is being developed to engage young people in their care and to lay the foundations for transfer into adult services. Such apps can allow access to individual records, information on core components of their care and advice on self-care and self-management for instance. The development of such technologies should be considered to support, but not replace, the roles of health and social care professionals in transitions of care.

Communication and coordination are critical across healthcare teams for the effective management of care for young people. The investment of time in building relationships across paediatric and adult teams will be critical to future successes of transfers of care. Establishing a cohesive matrix of healthcare teams to underpin effective care for young people will be important in paediatric care and to support transfers to adult services.

The concept of having a **named person/champion** at local levels with responsibility for implementing the transition guidance is imperative for successful implementation and improvements in the transfer of care from children to adult services.

The role of a **youth coordinator** is vitally important to transition of care. The concept of putting in place youth coordinator roles, on an area basis or condition-specific basis (depending on what is appropriate) could help to add value to the transitions of care. We are aware of examples of this which have been well received by service users, clinicians and service providers. Acting as a conduit between service users, their families and services, the coordinator can play an important role in managing the transfer of care, taking account of service delivery options and the preferences of service users, their families and carers.

We would welcome further engagement and would like to keep updated on the progress of the study.