## Preparing for the development of neurology specific principles of good transition across the lifespan

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### Overall aim

To develop a neurology specific set of principles incorporating illness experience, developmental and lifespan transitions and social and cultural transitions embedded within a good practice framework which would be applicable to people living with neurological conditions across the life-span. To achieve this goal a number of steps would be required.

## Phase 1

The first step was to undertake a systematic review of published literature reviews.

**Working definition of transition**

Before embarking on a systematic review however it was considered important to establish a working definition for transitions. The team agreed to adopt the definition based on research by Jindal-Snape (2016, 2018).

> ***"Transitions can be defined as an ongoing process of psychological, social and educational adaptations due to changes in context, interpersonal relationships and/or identity. This can be simultaneously exciting and worrying for an individual and others in their lives and may require ongoing additional support".***

To ensure consistency when referring to transitions it was also recommended that this working definition should be adopted for use during discussions with the Scottish Government and any future research.

Using published evidence an infographic was developed to summarise the multifaceted nature of transitions (Appendix 1).

### Systematic review of reviews

A systematic review of literature reviews was undertaken to appraise the evidence available in relation to the effectiveness of transition interventions which have been used with individuals who have a neurological condition. To ensure currency the included reviews were limited to the last decade. The findings will be disseminated using a variety of outputs and used to inform future research.

### Phase 1 recommendations

From the synthesis of the data the following recommendations have been made:

- individuals with a neurological condition, care-givers, parents, guardians, partners and health care professionals should be given a voice so that greater understanding and appreciation of transition experiences can be achieved,
- future research should focus on evaluating models of transition for those with a neurological condition and the effectiveness of implementation of transition practices across the life-span,
- standardised metrics should be used to allow greater comparison between and within groups,
- outcomes should be routinely evaluated with the addition of extended follow-up periods to ensure thorough evaluation of the impact of transition and
- multi-faceted transition experiences of individual's should be assessed.

As part of the research findings a number of principles of transitions were found. These provided a useful basis for understanding the steps involved in transition and its complex nature.

### Summary of the principles of transition

The following list of principles of transition have been devised based on principles published by several authors (Lewis et al 2010; Chambers 2015; Brown et al., 2016; ARC Scotland 2017; Kerr et al., 2017):

- Person centred with early contact (13 -14yrs) and involvement of young person in preparation for transition to adult services,
- Scheduled clinical encounters with adult services on an annual basis,
- Evaluation of the transition process which extends into adulthood for a number of years for example until the age of 25 years,
- Access to relevant information for all of those involved in transition e.g. young person, parents, guardians, caregivers, employers, service providers,
- Support for families adjusting to changing roles during transition processes,
- Regular and meaningful review of the effectiveness of service provision and strategies to promote independence and self-care with direct involvement of service users,
- Self-management skills regularly assessed and recorded ,
- A comprehensive transition plan that meets the needs of the individual (The plan should address: health care, finance and legal concerns, primary care, other specialty care, education, employment, housing, and community services) and
- The multidisciplinary approach should be extended to include meaningful involvement of the general practitioner/primary care physician.

## Phase 2

Based on the findings and recommendations from Phase 1 the aim of Phase 2 is to gather experiential data from those who have experienced transition (life transitions e.g. education, employment, health and social care transitions). The results will be available in March 2022.

**Appendix 1**

# TRANSITION

Transition is by definition a process. In published literature related to the healthcare management of those with chronic physical and medical conditions the term transition is used to define two entirely different concepts. These can be categorised as 'life' transitions' (developmental or experiential) or 'healthcare transitions' (transitional care ).

## LIFE TRANSITIONS

On-going

Psychological impact

Social and educational adaptations

Interpersonal relationships

Identity

Employment

Education

Retirement

## HEALTHCARE TRANSITIONS

An event

Person centred

Purposeful

Planned movement

Co-ordinated

Flexible

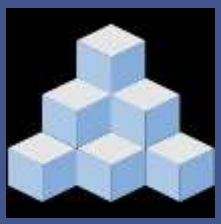
Comprehensive

Movement across services

## MULTIPLE AND MULTI-DIMENSIONAL TRANSITIONS

Multiple transitions can occur together

Individual experiences



Interconnected with significant others

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