Background The importance of effective and well managed transition care has been increasingly recognised along with the reality that for many it is poorly experienced. National and International policies have emphasized the importance of addressing these shortcomings. Individuals with the rare genetic disorder, 22q11.2 deletion syndrome (22Q11DS) face particular challenges with transition. By virtue of their genetic condition, they are at a highly increased risk of psychiatric disorders along with a variety of medical and educational problems, with the majority experiencing mild intellectual disability, all contributing to unique challenges of transition into adulthood. To date, the experience of these young people navigating this journey has not been well researched.

Aim This current project seeks to understand the experiences of a group of young people (Young Experts by Experience Panel, YEEP) as they journey from adolescences to adulthood, interfacing with many different healthcare providers. It seeks the views of YEEP as to methods to optimise this experience, and presents a practical transitional toolkit, designed by the YEEP.

Method Young people were recruited via the national support organisation following ethical approval. A semi-structured interview schedule was devised and guided participatory action research regarding transition experience and suggestions for future improvements.

Results The overwhelming experience by YEEP members was of a difficult and stressful transition, with poor transfer of information between services and an overall lack of knowledge by the new service providers of their unique needs and disorder (22Q11DS), requiring multiple retelling of their story. Their key recommendations was to develop a 'Transition Toolkit' to assist in the process, acting as a conduit of information from one professional to another, an aide memoir for themselves documenting key appointment dates and treatments and to which they could add useful information and resources. Details of the content/format of this will be presented.

Conclusion Optimum transition experience is critical to engagement with the new services, management of the medical condition and overall quality of life. Such care should be planned and co-ordinated, with the young person central to the process, and assisted by the family and clinical teams. Transition training for professionals coupled with the transition Toolkit, should assist in this endeavour.

Acknowledgements Support given by Ms Anne Lawlor, Chairperson of 22Q Ireland, and the members of the YEEP group which made the SSRA experience so enriching. This work was carried out as part of medical student elective. (DL 3rd year GEM - presenter)