story materials use, compared to non-usage, and that staff are finding the items useful in supporting communication and engagement. **Conclusion:** Results from this study will be used to develop a life story protocol for wider use among residents with dementia and ID.

Aging in persons with Down syndrome: attention, memory and executive function assessment

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Aim: Our gain was to develop specific measures to assess cognitive function in the aging process of people with Down Syndrome (DS) and detect neuropsychological changes related to age and gender. **Methods:** Ninety persons with DS (20–47 years old) were recruited from the Aura Foundation. They receive supported employment opportunities on their regular jobs in the open labor market. The sample was divided into two age groups: A â‰¤35 years old and B > 35 years old and each group were divided into male and females. The Screening Aura of Neuropsychological Assessment (SAS-NPS) was applied to all the participants. It evaluates cognitive functioning, including attention, memory and executive functions. **Results:** No differences were found between age groups or gender for attention, executive functions and recall memory. Group B showed significantly ($p < 0.006$) lower recognition memory, whereas men showed worse results ($p < 0.031$) than female and group A (both genders). **Conclusion:** It is important to follow the aging process through cognitive evaluation to detect changes that appear in adults with DS. While cognitive functions decrease over time in people with DS, the results of the present study provide evidence that regular job activity can prevent cognitive decline and promote active and healthy aging.

Towards onset prevention of cognition decline in adults with Down syndrome: the TOP-COG study

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Aim: This was the nested qualitative component of a pilot randomised controlled trial (RCT) of simvastatin for the primary prevention of Alzheimer disease (AD) in older adults with Down syndrome. The main purpose of the qualitative interviews was to identify ways we can improve on the processes of the trial for participants in the definitive trial, and to identify ways to improve recruitment and retention in the trial. We aimed to gain an understanding of participant and carer views on decisions regarding research participation, randomisation, and on experiencing the neuropsychological assessments. **Methods:** Semi-structured interviews following flexible topic guides are being conducted with ~20 participant/carer dyads ($n = 10$ who participated in the RCT, $n = 10$ who declined).The analysis is guided by the framework approach. As such, the analytic process is simultaneously inductive and flexible, therefore allowing key themes to emerge. **Results:** Interviews and analysis are in progress and will be available for presentation at the conference. **Conclusion:** We consider that studies such as this form an important part of the evidence base if we are to better understand how to engage people with intellectual disabilities, their relatives and carers, and service providers in research, and improve our knowledge exchange responsibilities.

Expressive vocabulary development in children with Down syndrome age 18–33 months: profiles and growth patterns

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Aim: Our poster presentation will present the expressive vocabulary development of young children with Down Syndrome (DS) with regard to modality (sign and/or speech), and nature of the vocabulary growth. It will also examine the role of cognition on vocabulary growth. **Methods:** We evaluated the expressive vocabulary of 31 children with DS aged between 12 and 24 months (age at start: $M = 16.5$, $SD = 4.2$) longitudinally over an 18-month period. Three modality (beginning, predominant sign, and sign and speech), and three growth (very little growth, linear growth, [non-linear] growth spurt) profiles of expressive vocabulary development were determined, as well as the relation between developmental quotient (DQ) and the onset of the vocabulary growth spurt. **Results:** Three different profiles were evident: a beginning profile, a predominant sign profile, and a sign and speech profile. Individual profiles may change in the course of vocabulary development. In 32.3% of the children a vocabulary growth spurt was observed, 58,1% showed a linear growth, and in 9,6% hardly any progress in vocabulary development was observed. **Conclusion:** Although most children with DS showed a 'predominant sign' profile, the variability in vocabulary growth patterns was considerable.

Safeguarding patients with intellectual disabilities in general hospitals against avoidable deaths and inappropriate commencement of end of life care

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Aim: Several UK inquiries found examples of discrimination and neglect of patients with intellectual disabilities (ID) in healthcare services, with avoidable deaths occurring due to poor healthcare. Our aim was to describe the factors that increase and reduce the risk of avoidable deaths and inappropriate commencement of end of life care for patients with ID. **Methods:** We conducted a 21-month mixed-method study involving 1251 participants (staff, carers and people with ID) in six hospitals in England. Data collection included questionnaires, interviews and observation. **Results:** Good practice was haphazard, with both good and poor practice observed within the same hospitals. As well as many positive examples, researchers found several cases where potentially curative treatment was not initially offered to patients with ID. Contributing factors to poor practice included: negative staff attitudes; assumptions about poor quality of life; lack of staff understanding of the law around mental capacity; and diagnostic overshadowing. Contributing factors to good practice included: active presence of an ID nurse for hospital patients; strong advocacy from carers; and good ward leadership. **Conclusion:** Strong professional advocacy and staff training are necessary in order to ensure that patients with ID for whom curative treatment may be possible are offered such treatment.

Disseminating research findings to non-academic audiences: 'How to break bad news to people with intellectual disabilities'

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Aim: An ongoing programme of research into the end-of-life care needs of people with intellectual disabilities (ID) led to the development of a new model for breaking bad news to people with ID, which was presented at the IASSIDD International Congress 2012. **Methods:** Feedback from research participants, in particular family carers and nurses in both ID and palliative care services, showed that the internet is a key medium for disseminating information and knowledge. Therefore, a new website was developed that includes not only information about the new guidelines, but also some practical examples and training materials. The website was successfully launched in October 2012, together with links to YouTube, Facebook, Twitter, and a non-academic book on the topic. **Results:** Early feedback suggests that both the website and the book are useful in helping families and professionals cope with bad news situation involving people with ID. The book has been translated into Dutch (published 2014). **Conclusion:** When disseminating research findings, it is important to find ways of reaching target audiences beyond the academic literature and conferences. The impact of dissemination strategies should be monitored.

Participation of people with intellectually disabilities suffering from dementia in residential facilities

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Aim: The prevalence of dementia in people with intellectual disabilities (ID) is at least twice as high as in the general population. As life expectancy increases for people with ID, the impact of dementia on these people and their families, careers and services is becoming more and more apparent. In this study we aimed to evaluate the following questions: How can community participation for people with ID be maintained despite dementia? **Method:** We conducted 12 interviews in facilities for people with ID in Lower Saxony. Interview partners were members of group home staff, facility managers and house coordinators. The evaluation of the interviews was conducted via content analysis as per Gläser and Laudel (2010). **Results:** Due to the fact that a dementia disorder in people with ID is accompanied by many problems, it is easy to imagine that the additional disorder leads to different needs. The implementation of appropriate support is becoming increasingly difficult with progression of dementia. This implies the risk of isolation of people with ID suffering from dementia. **Conclusion:** Crucial to the support of people with ID and dementia is the ability of services to develop the dementia competencies necessary to support those affected.