



## IDS-TILDA gains new insights with computer-aided interviewing

*Developing accessible interactive surveys to understand the needs of older people with intellectual disabilities*

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### Overview

#### The need

IDS-TILDA aims to give policy-makers insight into the needs of older people with intellectual disabilities (ID). Gathering data from this vulnerable population in a sensitive and ethical way was a key challenge.

#### The solution

The IDS-TILDA team used IBM® SPSS® software to design an accessible survey, and developed complementary supportive graphics for persons with low literacy to help illustrate many of the questions. Text-mining and statistics tools were then used to analyse the collected data.

#### The benefit

Computer-aided personal interviewing helps interviewees participate more fully in the study. Descriptive statistics and regression analysis provided new insight into the ageing ID population. Text analytics reveals common themes in free-text data entries.

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IDS-TILDA (The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing) is a research project that aims to help Ireland's government, voluntary and healthcare sectors gain a better understanding of the needs of older people with an intellectual disability (ID).

Eilish Burke, Project Manager at IDS-TILDA, explains: "The Irish Longitudinal Study on Ageing (TILDA) is a ten-year longitudinal study designed to understand the key determinants of health and well-being of older adults, and to help policy-makers plan for Ireland's ageing population.<sup>1</sup> The Intellectual Disability Supplement to TILDA (IDS-TILDA) focuses on the specific needs of people with an intellectual disability (ID) as they get older, and will ensure that there is comparable data on people with ID to inform those policy discussions."

In order to compare how people with life-long disability aged in comparison to the general population IDS-TILDA adopted many of the same protocols as the main TILDA project. Its survey instrument covered the same main areas of inquiry – including socio-demographic information, family and community life, physical and behavioural health, mental health and cognitive function, utilisation of health and social care, employment, education, daily life, and beliefs around ageing.



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## Solution Components

### Software

- IBM® SPSS® Data Collection Base Professional
- IBM SPSS Interviewer
- IBM SPSS Statistics
- IBM SPSS Text Analytics for Surveys

### IBM Business Partner

- Presidion
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## Recruiting a representative sample

“The first challenge was to gain ethical approval from all the relevant authorities, which included Trinity College Dublin and 138 separate intellectual disability service providers,” says Burke. “Once the approvals were in place, we were able to send out invitation packs to potential participants and ask them or their family members or guardians for their consent.”

In total, 753 people aged between 41 and 90 were recruited into the sample. This is 8.9 percent of the total population of people aged 40 or over who are registered in Ireland’s National Intellectual Disability Database.<sup>2</sup>

“The TILDA project recruited people who are over 50, but IDS-TILDA chose 40 as the minimum age because people with ID often present age-related health conditions at a younger age,” says Burke. “For example, the onset of Alzheimer’s disease is generally earlier in people with Down syndrome than it is in the general population.”

## Being sensitive to participants' needs

Due to the vulnerable status of many of the people in the sample, and the difficulties created by their pre-existing intellectual impairment and communication difficulties, IDS-TILDA needed a survey instrument that was accessible and non-threatening to people with an ID.

Similar to TILDA, the team recognized that a computer-aided personal interview (CAPI) strategy would be the most effective way to help respondents participate as fully as possible.

“CAPI was the right approach because it would allow us to give the participants a lot of support throughout the interview,” says Burke. “Rather than a huge, intimidating paper questionnaire, we could run the survey tool section by section on our laptops and guide individuals through the interview one question at a time.”

This approach also made it possible for family members or long-term carers to help participants who were not able to complete the survey on their own. Various levels of proxy support were possible – from occasional help with particular questions through to the proxy completing the whole survey on the participant’s behalf.

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— Eilish Burke, Project Manager, IDS-TILDA

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### **Developing an accessible survey**

Presidion, an IBM Business Partner that specialises in IBM Business Analytics and Predictive Analytics solutions, worked with the IDS-TILDA team to operationalise administration of the survey using IBM SPSS Data Collection Base Professional software. The survey was then deployed on laptops using IBM SPSS Interviewer.

“SPSS Data Collection gave us the ability to design a very clear, accessible mechanism to administer the survey, which helped to make the interviews more enjoyable for our participants,” says Burke.

“One of the biggest advantages was the ability to use large fonts and to link the questions to the supportive showcards that we developed to illustrate the questions. Out of all 753 interviews, there was only one person who preferred to use a paper questionnaire instead of the laptop.”

She adds: “Presidion really helped us to take the survey we had created and embed a logic and delivery process into the questionnaire. For example, if the answer to one question implies that the subsequent follow-up questions aren’t relevant, the survey will skip them and move straight on to the next section. There was no turning of pages, which saved a lot of time during the interviews and increased accuracy.”

Presidion’s help also increased flexibility. Respondents could answer the questionnaire one section at a time, in any order they chose, and were able to take a break at any point. At the same time, the built-in validation rules ensured that each section was completed fully and accurately. Moreover, if an interviewer entered an invalid answer or used the wrong format, those same internal validation rules prompted a pop-up message asking them to check and correct the data.

### **Easy integration between tools**

With the first wave of surveys complete, the IDS-TILDA team imported the results into a suite of analytics tools, including IBM SPSS Statistics for statistical analysis of quantified data, and IBM SPSS Text Analytics for Surveys to mine qualitative information from the survey’s free-text fields.

“The integration between the SPSS products is excellent, so it was very easy to move the data from the survey into the analytics tools,” comments Burke. “The data is all validated at the point of entry, so there were very few issues with missing information, making the data ready for analysis and ensuring that our results were much more robust.”

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### **Enriched insight with text analytics**

The ability to use the text-mining capabilities of IBM SPSS Text Analytics for Surveys has opened up new possibilities for analysis.

“This is the first time we have used text-mining, and it’s a great way to enrich and elucidate the quantitative data with additional detail,” says Burke. “It has enabled us to capture participants’ thoughts and opinions and track the occurrence of common themes across the sample – even when the language they use is not always clear.”

With SPSS’s ability to create custom dictionaries, the IDS-TILDA team was able to categorise the vocabulary used by survey respondents and connect it to specific concepts such as their thoughts and beliefs about ageing. The team then used the software to create visualisations that mapped out the respondents’ most common concerns, and make it easier to assess the links between them.

### **Looking to the next wave**

Presidion is supporting IDS-TILDA for the second wave of surveys by helping to re-standardise the questionnaire after some updates to the questions, and then optimise it for analysis. The IDS-TILDA team is now revisiting the original participants three years after their initial interviews.

“730 of the original 753 participants are being interviewed in wave two, so we have retained 97 percent of our sample,” concludes Burke. “If people had not enjoyed the interview process, it’s likely that fewer of them would have agreed to participate a second time. The CAPI approach has been a real asset.

“We’re excited to see the results as each new wave is completed, as it helps to build up an ever more comprehensive picture of what life is like for people with an intellectual disability as they grow older in Ireland.”

### **About Presidion**

With a client base spanning hundreds of public and commercial organisations, IBM Premier Business Partner Presidion is one of the leading providers of analytics services in the United Kingdom and Ireland. With world-class expertise in IBM SPSS solutions, Presidion helps its clients to use advanced analytics technologies to make more accurate, evidence-based business decisions.

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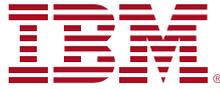
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1. Barrett A., Savva G., Timonen V. and Kenny R. (eds.) (2011). *Fifty Plus in Ireland, the first results of the Irish Longitudinal Study on Ageing*. Dublin: TILDA.
  2. McCarron, M., Swinburne, J., Burke, E., McGlinchey, E., Mulryan, N., Andrews, V., Foran S. and McCallion, P. (2011). *Growing Older with an Intellectual Disability in Ireland 2011: First Results from The Intellectual Disability Supplement of The Irish Longitudinal Study on Ageing*. Dublin: School of Nursing & Midwifery, Trinity College Dublin.
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