

# The Sage-ID Study

Edition 1, 24th June, 2013

Dear **Participants, Carers and Friends**,

**Welcome** to Edition 1 of the Sage-ID newsletter.

Firstly, we would like to take this opportunity to **thank you** for your participation and support of the study. The study began two years ago, and is looking at health in people with intellectual disability as they get older. We hope we can help to inspire positive change within the lives of people with intellectual disability and their families. It is due to **your** help, enthusiasm and participation that we have got as far as we have today.

We hope you enjoy reading and as always, please don't hesitate to contact us if you have any questions or concerns.

Yours sincerely,



A/Prof. Julian Trollor  
and the Sage-ID team

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Online, visit our website at:  
<http://3dn.unsw.edu.au/project/successful-ageing-intellectual-disability-sage-id-study>

Or Facebook page:  
<http://www.facebook.com/sageid>



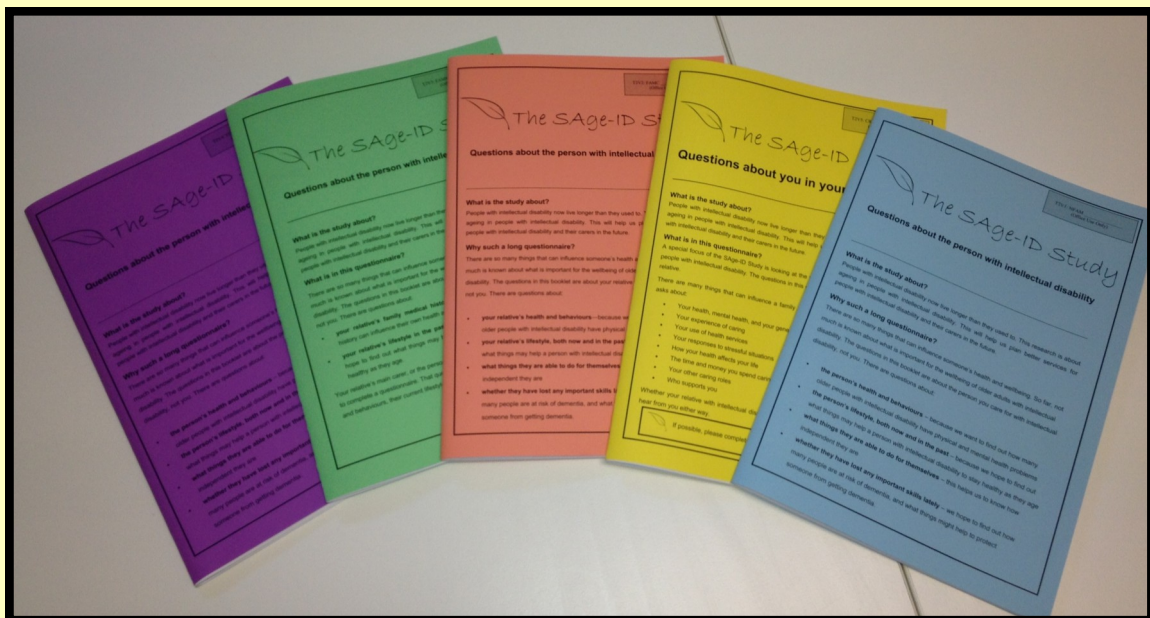
Or Wiki page:  
[http://en.wikiversity.org/wiki/Ageing\\_and\\_intellectual\\_disability](http://en.wikiversity.org/wiki/Ageing_and_intellectual_disability)

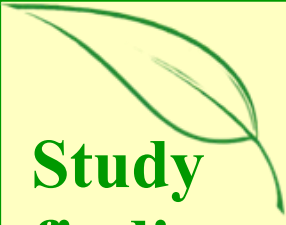




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## Study findings

WAVE 1  
127 Expression of  
interest forms received

77 Questionnaires about  
the person with  
intellectual disability  
completed

40 males and 37 females

- ♦ The average age of our participants is 52 years.
- ♦ Almost half of our participants live in small residential facilities, while about a third live at home with relatives.
- ♦ Many of our participants are actively employed; almost half of our male participants and a third of our female participants currently have a job.
- ♦ Only around one quarter of participants had a known cause of their intellectual disability. Out of these, non-genetic causes were more common than genetic syndromes.
- ♦ The most common health concerns in our sample were high blood pressure and high cholesterol, each reported in about a third of participants. Only half of the people who had these problems were taking medication to control them.
- ♦ Diabetes was also common, reported in about one fifth of participants. This diagnosis was more common in men.
- ♦ Around two thirds of the sample had a body mass index that placed them in the overweight or obese category.
- ♦ Alcohol use within the sample was infrequent, with most participants drinking once a month or less.
- ♦ Women were more likely to smoke than men, but only one in every 10 participants were smokers. This is much lower than the overall rate for Australia.

## **Sage-ID Study News — New target areas in NSW!**

After two years of recruiting in Rockdale, Botany and Randwick the study areas have now extended to all of Sydney Metro South. This includes the following areas:

*Waverley, Woollahra, City of Sydney, Leichardt, Ashfield, Burwood, Strathfield, Canada Bay, Canterbury, Marrickville, Hurstville, Rockdale, Kogarah, Botany Bay, Randwick, Sutherland, Campbelltown, Fairfield, Liverpool, Camden or Bankstown*

This is very exciting as it allows many more people to be involved in the study. With more participants, we can increase the strength of our study results.

The people living in these areas who previously said they wanted to participate will be contacted soon.

In Victoria, the regions covered are still *Bendigo, Shepparton, Loddon, Swan Hill, Mildura or Macedon Ranges*



*The NSW Sage ID team celebrating the first questionnaire returned, back in 2011. From left— Daniel Pua, Liz Evans and Kate Chitty*



## Embracing Life and Ageing Well

Community forums have been held in **NSW on October 30th 2012** and **Victoria on February 13th 2013**. Panel members included, Ms Sam Mostyn, Dr Seeta Durvasula, Prof Christine Bigby, Prof Jane Farmer, Dr Jennifer Torr, Prof Teresa Iacono and A/Prof Julian Trollor.

The forums brought together people with intellectual disability, their families, friends and carers as well as service providers from the disability, health and mental health, and aged care sectors.

The main focus of the forums was to increase awareness of the need to promote the physical and mental health needs of people with intellectual disability as they age, and ways to achieve this.

Speakers also highlighted practical support available for carers and people with intellectual disability and where to go to seek this.

The forums provided an excellent opportunity for attendees to hear personal experiences, and advice from leading experts. During the buffet dinner there was a chance to mingle with our team members, the other speakers and of course other individuals and families.

Many thanks to the panel members, the organisers and all those who attended for making these forums such a success.

See our wiki page for videos from the Victorian forum:  
[http://en.wikiversity.org/wiki/Ageing\\_and\\_intellectual\\_disability](http://en.wikiversity.org/wiki/Ageing_and_intellectual_disability)



*The speakers panel at the NSW Community Forum on October 30th, 2012: From left—Sam Mostyn, Dr Seeta Durvasula and A/Prof Julian Trollor*

# Team Member Profiles

**Kate recently interviewed two Sage-ID team members to find out what makes this a rewarding job for them. Here are their stories.**

**Name: Natalie Crothers**

**Role:** Research Assistant and PhD student

**Site:** Victoria

I am currently enrolled in my PhD at La Trobe University which is looking at dementia and intellectual disability. My PhD aims to map pathways to care for people with intellectual disability and dementia and compare these pathways to people with dementia without intellectual disability.



*What do you like most about working on the study?*

I enjoy the contact I have with family carers, key workers

working in disability and the various organisations. They provide a lot of their time in assisting with our research, and their contribution to the understanding of the health and wellbeing of adults with intellectual disability is very valuable. Often we hear of the difficulties families and disability organisation face, but we also hear the stories and aspects that are working. I hope this study will benefit not only those families and disability organisations that have dedicated their time to be a part of the study but many more facing the same issues.

**Name: Beth Turner**

**Role:** Research Assistant

**Site:** NSW

*What do you like most about working on the study?* I enjoy the contact I have with participants. I have conducted face-to-face assessments with some of our



participants at the centre. Every assessment is as unique as the individual who attends, and I enjoy the time we spend doing different tasks.

I spend a lot of time talking to family carers and paid carers on the telephone. The carers are diverse in their life experiences, and are generous with their time despite leading very busy and often stressful lives. I like talking to people, hearing their story and finding out what the research project means to them personally. The study would not be possible without the enthusiasm, generosity and dedication of our participants.

*What sort of impact do you hope this study will have in the future?*

One clear message I have heard from carers has been that they feel older people with intellectual disability are often forgotten about. They have fears about what will happen as they age, and who will look after them in the future as their needs change. I hope that this study illustrates the needs of this population, and that it gives a voice to carers.