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Assessing knowledge, planning for and fear of death

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Aim: Few self-reporting instruments about dying and death are available for people with intellectual disabilities (ID). The Dying to Talk project in Sydney, Australia measured knowledge about death, understanding and self-determination of end-of-life planning, and fear of death. This paper reports on the instruments used. **Method:** We describe the use, adaptation, piloting and content of these instruments, including development of a new instrument on end of life planning. Participants included 39 adults with ID and 40 adults without ID (disability staff). All were assessed by individual interview on all three instruments. A sub sample was scored independently by a second rater. **Results:** Internal consistency and inter-rater agreement were good for each scale. People with ID were willing and able to provide scorable answers for almost all items, with a higher level of non-response on certain fear-of-death items. **Conclusion:** We found the instruments were usable, reliable and valid for people with and without ID. Availability of such instruments will facilitate future research, intervention and practice.