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Abstract
This is a cross sectional study in 5 GP Training Practices, sample size 100 clinically stable patients, attending for routine care. Purpose of the study was explained and informed written consent was sought. Participants were provided with ‘Think Ahead,’ an innovative end of life planning tool, devised by The Forum on The End of Life, based on best international practice, presented in a questionnaire format, detailing main decision centres relevant in end of life planning. Participants completed telephone surveys at 1 and 3 weeks, ascertaining their experience with ‘Think Ahead’ 92/100 completed both surveys. Results indicate high levels of acceptability and positive experience for most participants. A majority (63%) indicated ‘no difficulty’ in completing ‘Think Ahead’ 74% indicated reported they did not find completing the folder to cause upset; 87% indicated they felt the folder should be more widely available, and 69% indicated they felt ‘Think Ahead’ would be of general interest. The study was effective in encouraging discussion on end of life issues with family(83%) with 49% indicating they had done so in detail, and 34% indicating having ‘done so somewhat,’ having read ‘Think Ahead’;27% indicated aspects of it were upsetting. Results will be used to inform further development of the tool. General Practice consulting is a suitable context in which to systematically present ‘Think Ahead.’

Introduction
End of life planning is recognised to be important in the care of healthy adults and individuals with significant medical conditions. Among the earliest references is Kutner (1969) (concept of the advanced directive). In Ireland, The National End of Life Care Programme (NELCPP) and Think Ahead were established to implement 6 steps in the end of life care pathway.1 Concern in this area of care is evident in terms of expressed wishes of patients and families, where difficulties are known to exist among familiar care pathways, for example in emergent out of hours care in the community. The National Council of the Forum on End of Life was established in 2009 in Ireland to stimulate discussion on end of life planning, and make recommendations to improve end of life care. The Forum work plan includes Think Ahead, formally launched in 2011. Think Ahead seeks to provide guidance for individuals formulating and recording of end of life wishes, preferences, and relevant care details, where possible to do so in consultation with family and friends and family, and making decisions more effectively available in an emergency, and in care after death. Think Ahead is available through Citizens Information Centres and online (www.thinkahead.ie). This study explores systematic use of Think Ahead in a General Practice setting.

Methods
A study was undertaken in 5 Practices on The TCD HSE GP Training Scheme. ‘Think Ahead’ was presented to 100 patients (aged 40-70 yrs) considered clinically stable, serially attending for routine care to their GP (i.e. GPs were instructed to invite all patients aged 40-70 years meeting the inclusion criteria were invited to participate). Patients adjudged by their GP to be presenting with acute clinical conditions were excluded (i.e. GPs were instructed to exclude patients who were acutely unwell, in pain, or otherwise experiencing distressing symptoms). Patients invited to participate were therefore clinically stable, attending largely for planned routine appointments (e.g. diabetic check), and understood to have been at no clinical risk. Patients with impaired cognitive function were excluded. Patients were recruited through provision of an information sheet, outlining purpose and nature of the study. Informed written consent was obtained. A printed version of Think Ahead was presented, and taken home by the patient. Patients were encouraged to complete Think Ahead with partners or family members.

Think Ahead includes an introduction and six sections – Section 1: Key Information (important contacts/insurance details etc.); Section 2: Care Preferences (place of death /life prolonging care, CPR, religious /cultural beliefs); Section 3: Legal (Wills/Enduring Power of Attorney); Section 4: Financial (Bank accounts/pension/life assurance details); Section 5: When I Die (wishes on organ donation, post-mortem, funeral arrangements); Section 6: Sharing of Information (consent for folder contents to be accessible to family, GP). Telephone surveys were carried out at 1-2 weeks and 3-4 weeks. Ethical approval was obtained from the TCD HSE GP Training Scheme Ethics Committee. It was run on a pilot basis, with minimal modification following the pilot, results of which are included.

Results
At week 3 the number of people who had fully responded was 92/100, (52 were female, 51 were medical card holders, most were aged 51-60 yrs). 97% of people read the document, and 76% completed either all (31%), or some (44%) of it.

Acceptability
A majority (63%) reported no difficulty completing the folder; 74% of people indicated they did not find completing the folder to cause upset.

Difficulty in completing ‘Think Ahead’
37% indicated some difficulty in completion, the principal area identified as difficult being the section entitled Care Preferences. A sample response was: ‘Dread and uncertainty regarding financial planning’.

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Upset in completing ‘Think Ahead’
Among 28% reporting upset, two main areas were identified. These were from sections When I Die and Care Preferences. The idea of organ donation and switching life support machines was upsetting, with 9 respondents (9.2%) identifying upset at thoughts of dying. When you are sick, you may feel differently about the choices you have made when you are well.

Recommendations for change by respondents
During telephone interview, participants were asked if they felt information should be removed from the folder. Most (84%) indicated they believed the folder should not be changed. A minority (8.4%) indicated particular information or questions should be removed from the financial section, particularly details regarding recording bank account details (5.4%).

Further items to be included
Most (69%) felt no additional information should be included or removed. Some respondents indicated additional information is needed to support people in making decisions to be contacted at time of death. Church or religious organisations to be notified, and guidance on how often the Think Ahead document should be reviewed. A majority (89%) indicated preference for paper document, 21% had no preference, and 13% indicating preference for a web based format.

Overall impression and recommendation
Overall, 87% felt that the Think Ahead document should be made more widely available. A smaller majority (68%) indicated it to be of interest, and 5% of respondents felt it was not likely to be of interest, with the remainder (27%) equivocal. When asked if reading the document had caused them to discuss end-of-life issues with their families, 49% of respondents reported that it had done so in detail, 34% reported somewhat, and 17% indicated it had not done so (Figure 1.).

Discussion
Research in Ireland indicates that patients, families and healthcare professionals are reluctant to discuss death and dying. It is also understood that failure to discuss end of life care contributes to unsatisfactory and distressing outcomes. In a national survey reported in 2004, a majority of Irish people (67%) indicated they would like to die at home, with a minority preferring to die in a hospital (10%) or a hospice (10%). However, at least half of all deaths occur either in acute hospitals (48%) or hospices (4%). Deaths at home constituted only a quarter of the total (25%), and a further 25% in log-stay facilities. Many patients (53%) indicated they would like more discussion around the issues of death and dying. It is elsewhere reported that when GPs are aware of the expressed wishes of patients regarding place of death, this is positively correlated with patients not being hospitalised in the last 3 months of life. Even where clearly stated patient preferences are documented, recent evidence indicates these are ignored.

A report from The National Confidential Enquiry on Patient Outcome and Death (NCEPOD) describing data from 524 cardiac arrests treated in hospitals (UK & Northern Ireland) reported 52 out of 524 patients actually underwent resuscitation attempts despite explicit decisions against resuscitation, recorded in their hospital medical record.10 Goodly levels of satisfaction and acceptability evident in this study strongly suggests that where GPs are guided with an appropriate communication tool, this improves communication around these issues, and thereby increase the probability of improved outcomes for dying patients and their families. This is important, given recognised and well described concerns of Irish patients in this area of care. Levels of engagement with Think Ahead in this study (76% indicating they completed all (31%) or part (44%) of the Think Ahead folder) compare favourably with those reported elsewhere. Ramasroop, in a systematic review examining completion rates for advanced directives in the primary care setting observed highest completion rates (44%) where interventions incorporated direct patient-healthcare professional interactions, over multiple visits.

Based on results from this study, it is recommended that provision of The Think Ahead Package in the general practice setting is an acceptable and useful intervention. Though it is clear a minority of respondents report some degree of upset and uncertainty regarding their engagement with Think Ahead, a majority did not. It is arguable that long term benefits of engaging with the process electively, in a timely manner, outweigh levels of concern evident in responses here. Moderate concern among a minority who are clinically stable is arguably preferable to acute distress and indeed the anguish known to arise, when there is little or no end of life planning, and where decisions are taken in haste, or in ignorance of patient preferences.

Limitations of this study include possibility of bias, given telephone surveys were carried out by the patients doctor. The study excluded patients adjudged to be clinically unstable (e.g. those with active medical problems or impaired cognitive function, where end of life planning is understood to be challenging). The current version of Think Ahead already reflects experience captured in this study, particularly in the causes of upset and uncertainty. Maintaining a limited folder on the GP electronic medical record, should the patient wish, in order to prompt periodic review, and to make it selectively available in the event of onset of complex or acute illness, in the out of hours setting. Given the extent (82%) to which GP medical records are known to be computerised,10 and strong links between GPs and GP Co Operative Services, it becomes possible to consider how expressed wishes of patients could be reliably communicated and available, to inform out of hours management decisions; the authors recommend this should now be explored, as in other healthcare systems.

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