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Designing the new integrated carer support service

Draft Service Concept

Department of Social Services

Submission from Alzheimer's Australia NSW

June 2016

Alzheimer's Australia NSW appreciates the opportunity to respond to the draft Service Concept for the new integrated carer support service. Alzheimer's Australia NSW is the peak body for people with dementia and their carers in NSW. We provide advocacy, support services, education and information. Our organisational mission is to minimise the incidence and impact of dementia through leadership, innovation and partnerships - in advocacy, policy, education, services and research.

NSW is the oldest member of the Alzheimer's Australia federation, dating back to 1982 when the organisation was formed as a carer advocacy group. This paper is therefore very pertinent to the original intention of the organisation and its current focus.

In summary, the key points of this submission are:

1. **Carers of people with dementia have needs that are similar and different to other carers – therefore responsiveness to individual need should be a key consideration.**
2. **The proposed integration may result in increased fragmentation for carers and benefits of the current system and approach may be lost eg. local knowledge, networks, collaboration, emphasis in some service delivery on both the carer and the person with dementia, specialised services focused on dementia.**
3. **The Principles and Design Considerations appear conflicted and mutually inconsistent in parts. This conclusion has been reached from the Service Concept appearing to: want flexibility, but is restrictive in places; enable choice, but provide a limited multi-component intervention; and be evidence-based, but allow carers to make choices. Which is 'right' from a public policy perspective? Which is more important?**
4. **There is apparent tension in the Service Concept between goal-based planning and needs-based allocation as a mechanism to allocate funding. It isn't clear which approach will be taken. With the broad range of carers, the person they are caring for, the changing needs over time – there may be an argument to have an approach that accommodates both. Carers often don't know what their needs are and have trouble articulating goals (which is often a difficult concept to grasp).**

In preparing this submission, Alzheimer's Australia NSW used the following methodology:

- Review of literature on dementia and carers aligned to the Design Considerations and Principles
- Conducted two focus groups with staff with representation from: management, Helpline, library, counselling, Younger Onset Dementia Key Workers,

evaluation, policy, education, early intervention, community development, outreach, Dementia Advisory Service and consumer engagement.
- Conducted a validation focus group with carers of people with dementia.

This submission focuses on two components of the paper released by the Department of Social Services:

1. Guiding Principles
2. Design Considerations

The submission responds to the questions posed drawing on the information gained in the methodology outlined above.

Preamble

Dementia (this term is used in this review to refer to Alzheimer's disease and related disorders) is a condition that affects a growing number of people in Australia as our population ages. Current estimates put the number of Australians currently living with dementia at more than 353,800, with that number expected to increase to almost 900,000 by 2050, without a significant medical breakthrough (AIHW, 2012). The Australian Institute of Health and Welfare estimates that 70% of people with dementia live at home. The progressively debilitating nature of dementia means that most people have a carer, who may be their spouse, partner, adult child, relative or friend to support and care for them.

A diagnosis of dementia has wide ranging implications for both the person who has the condition and those who care for them. For both the person with dementia and the carer, it means understanding how their cognitive decline will impact on their daily life and the prognosis for the condition, finding ways to maintain self-esteem and independence (Husband, 2009 cited in Moniz-Cook and Manthorpe, 2009), as well as forming a new sense of "self" and their future (Lipinska, 2010). The impact of the diagnosis can result in depression for the person with dementia and carer (Yale, 1995). For those close to the person with dementia, it means someone taking on the caring role and all that entails, which may happen gradually as the condition progresses (deVugt and Verhey, 2013). The progressive nature of dementia means that caring demands increase over time. Carers experience psychological, physical, social and financial effects as a consequence of their caring experience (Brodaty and Donkin, 2009). In fact, the impact on the lives of carers is reported to be greater than for those who care for people with physical disabilities (Mittelman, 2013).

In the past three decades, a wide variety of non-medical, psychosocial interventions have been developed, the majority of which have focused on supporting carers by decreasing the negative impacts of caring in order to reduce psychological distress and enable carers to care for longer (Gallagher-Thompson, et al. 2012).

Olarzaran et al. (2010) reviewed 176 randomised control trials of non-pharmacological interventions for both people with dementia and carers. The carer interventions included education, coping skills training, support groups and multi-component studies. Their conclusion was that non-pharmacological interventions "emerge as a useful, versatile, and potentially cost-effective approach to improve outcome and quality of life in Alzheimer's disease and related disorders for both the person with dementia and the caregiver" (Olarzaran et al., 2010: 162).

Gallagher-Thompson and Coon (2007) examined nineteen interventions that were underpinned by psychological theories of change. They found that psycho-educational interventions which focused on skill training and education, psychotherapy interventions based on CBT and multi-component interventions using a combination of at least two theoretical approaches such as individual counselling and support group participation were effective.

Elvish et al. (2013) found that interventions based on cognitive-behavioural models can produce meaningful results for carers. Evidence also supported interventions that aim to increase dementia knowledge and improve communication. Therapies that consisted of multiple components, such as individual and family counselling and support group participation and technology-based interventions that combined both group and individual sessions were found to be most effective. To enhance the effectiveness of these interventions they should be either tailored to individual needs or group interventions focused on a common issue.

While it is an accepted truth that carers require support for their well-being and to sustain the caring relationship, which types of supports are the most suitable for which carers is still unclear (SuccessWorks, 2011). Thompson et al. (2007:12) asserts that in terms of the quality of current evidence available "there really is a need for radical scrutiny of what exists and what we can learn from well-constructed evaluations".

Alzheimer’s Australia NSW therefore supports investment by Government in evaluations of specific and multiple interventions. This will become particularly important as the Government funding shifts from block/output based funding to individualised/consumer controlled expenditure. Key questions will be: are consumers’ choices effective; and do consumers’ choose services that are shown to be the best according to the available evidence?

Guiding Principles

The consensus view formed in the focus groups was that the Guiding Principles seem appropriate at first glance. Once people started to question what was actually intended by some of the Principles, further debate ensued about what the detail might look like that sits behind these overarching statements.

The following questions were raised in the various focus groups:

- How will this new program align with other programs? In some areas it seems to be at cross-purposes with other reforms, however, there would also seem to be opportunities to interface with other Gateways and maximise the benefit of this through integration with other systems.
- For whom will the services be cost effective, what metrics would determine this and what is this driving at? The current Government investment in carers equates to an average of $1,000 per carer per annum (not including Carer Payments detailed in Annex C). If there is increased awareness and uptake by carers who are currently 'out of the system', will this figure decrease or would the overall Government investment increase to meet the greater expressed need? Following on from this, what would be the consequence of not spending an average of $1,000 per carer per annum and what might the adverse consequences of this be (social, economic, political)?
- How will equity of access be achieved? The paper is very scant in detail about this and neglected to include details about special needs/disadvantaged carer population groups.

The central principle of having a focus on carers is appropriate for this program and is supported. Concern was raised about the assumption of benefit for carers that underpins the philosophy of a dedicated carer-focused support service. One of the strengths of the National Dementia Services Program suite of services and activities is that they recognise and include both the person with dementia and the carer (where possible and appropriate). This recognises the often mutual dependent nature of the relationship and that the caring role is often linked to the context and stage of progressive decline associated with dementia. In saying this, one of the strengths of the proposed carer support service is that it recognises that a carer will have separate needs at different times, which warrants an individualised response.

Another concern is the seeming limitation to supports being available for primary carers. Alzheimer's Australia NSW is very much aware that dementia impacts the whole family and the need for some of the supports described in the Department's paper will also benefit family members e.g. information, education, peer support, counselling. This is particularly the case for children of people with younger onset dementia who find their parent is changing while they are at high school and many of the experiences their friends have and the relationship with both their parents is different to their friends.

Reference to the work of Walter Leutz and his Five Laws of Integration is instructive with the Department using the word 'integrated' in the program title. The Laws are:

1. You can integrate all of the services for some of the people, some of the services for all of the people, but you can't integrate all of the services for all of the people.
2. Integration costs before it pays.
3. Your integration is my fragmentation.

4. You can’t integrate a square peg and a round hole.
5. The one who integrates calls the tune.

While Leutz’s work focused on clinical and long-term care models, there is relevance and applicability to the proposed ‘integrated carer support service’. This is particularly the case with:

- The integration of this carer service with other reforms in aged care, disability, mental health and chronic disease management.
- The carers who are currently accessing supports and service providers who are delivering them will experience fragmentation through the move to a new model. For example, carers will have established patterns of service use and interactions with staff that will be disrupted by having to proceed through the Gateway in future. A strong communications strategy to existing carers would aid in this transition phase. The experience of both the NDIS and aged care reforms is instructive in how to, and how not to, communicate with people about reforms that impact on them.
- There is not one universal carer experience and need, therefore, it will prove impossible to integrate all of the services for all of the carers in Australia who care for a very large range of disabilities, diseases, illnesses and frailties.
- The tension between who is integrating the services – is it the Government or the carers? Who will be calling the tune of integration and whose interests are being pursued through this process?
- There is evidence that consumers choose what they know. Will they be given freedom of choice to integrate their services as they wish? This would maximise the flexibility and responsiveness of the carer support service, but may not capture the benefits of total integration with MyAgedCare or NDIS services (which are the primary program for people with dementia).
- Carers must have choices in the new program and it should not be overly prescriptive. A problem-solving, guided decision-making approach – not directed - has worked successfully in other programs delivered by Alzheimer’s Australia NSW.

Service Concepts

Awareness

> *“the most crucial support phase is Awareness - if that step isn't fully supported and funded, then it's likely the program won't make the hoped inroads into the unreached carer population” Carer*

Issues identified in the focus groups related to awareness are that:

- carers do not identify as ‘carers’ so any efforts to promote this would need to be communicated in a way that resonates with the target audience.

- At the point of diagnosis of dementia, there is value in introducing the concept of being a carer.
- The process of self-identification is one of gradual change and acculturation to the concept. Existing carers and peer communications are seen as effective mediums to promote awareness.

Information

An approach identified in the focus group with carers is that any information delivery needs to be structured to the carer's thinking and the way they conceptualise information – and this may be related to the stage of dementia the person they are caring for is at. A study of 110 carers by Alwin et al. (2010), found that two types of support services perceived as very important by carers were information about dementia and information about support available and how to access it. Not having knowledge of available support has been identified as one of the barriers to utilisation of dementia services (Vetter et al., 1998).

NDSP programs largely fulfil this need for carers, including carer and family group education. Integration of NDSP services with the IPCSS will therefore be critical in order to be effective in addressing carer information needs.

Intake

Intake will need to be a continuous process because of the progressive decline of a person with dementia and the subsequent changing circumstances for their carers.

Issues identified in the focus groups that may make intake hard are that:

- Carers may provide incomplete information, or understate their true need.
- Carers may be too overwhelmed at the particular point in time that intake occurs

Being reactive and proactive to connect with carers would be helpful, particularly for those who are often reluctant to reach out for help. Participants in the focus groups questioned the capacity of the Carer Gateway to do this, but felt it was important that this functionality be attained. This would help provide a holistic model that is conscious of what the carer will listen to and act on, where to go, what the priorities for them are and what goals they expressed for themselves.

Needs Identification and Planning

Following on from the above comment about goals, participants in the focus groups all felt that goal based planning should be optional for carers. Development of goals and articulation of these was perceived to be quite challenging for a lot of carers. The amount of distractions and focus on the person with dementia was seen to override any focus on their own goals. Literature on carers supports this focus on people other than themselves, to their own detriment.

Focus group participants also queried the timeframes / periods for re-assessment. How long would this be? Could this be initiated by carers?

A model that has been implemented by Alzheimer’s Australia that has incorporated both goal-based planning and a needs based assessment is the Younger Onset Dementia Key Worker Program. This has worked with carers, family members and people with dementia to assist people with planning, accessing formal and informal supports, counselling, information and education support.

The use of self-assessment is supported from a philosophical perspective and the paper from the Department outlines how it is consistent with consumer directed approaches. Alzheimer’s Australia NSW is supportive of this. However, the issue of attaining equity of access to supports is a concern as people will have different felt and expressed needs that could result in different allocations of individualised support. A practitioner-led assessment (normative and comparative needs) may, however, identify that two carers have the same need for supports, but their self-assessment results are different. Bradshaw’s (1977) taxonomy of needs is instructive in this regard.

Counselling

People with early dementia face enormous challenges in coping with their condition, yet they typically receive little personalized education or support following the diagnosis. Counselling and support can help families keep people with dementia at home and that competent emotional support and referral resources can reduce the negative impact of caregiving on the caregivers. Counselling empowers them to understand and come to terms with the illness while also learning to manage and make healthy adaptations to it. Counselling assists people with early dementia and their carers to:

- work through complex emotions
- tap into useful coping mechanisms
- focus on capabilities
- adapt to practical circumstances in their day-to-day activities
- retain maximum autonomy over lifestyle preferences
- find new ways to move forward with their lives

A person-centred counselling experience can therefore have positive outcomes for those with dementia and the people who care for them. When considering various counselling approaches, CBT has the strongest evidence base in terms of effectiveness in treatment of anxiety and depression.

In saying this, the views expressed by Alzheimer’s Australia counsellors and Helpline staff are that Solution Based Therapy is more appropriate for short-term interactions, such as Helpline calls. Further, some counselling techniques needs a specific ‘dose’ to be effective. The staff expressed a view that any approach works in an evidence-based approach, but is dependent on the individual receiving counselling and the reason for presenting.

For the carer, counselling can address issues of stress and depression, as well as provide information and strategies for coping with the constantly changing nature of dementia, understanding behaviours, accessing services and working through transitions in their caring experience, such as the changing relationship with the person with dementia and the move to residential care (Griffiths 2010).

Thus, a counsellor can provide support across the lifespan of the condition, assisting the carer to adapt to the demands of being a carer and cope with grief and loss during the course of caring as well as after the person they are caring for dies (SuccessWorks, 2011). Brodaty et al (2003) found qualitative results which indicated structured individual counselling and provision of a constant professional who could provide flexible ongoing support had benefits for the carer. The model used by Alzheimer’s Australia NSW is responsiveness to client need. Therefore, solution based therapy is the dominant technique used because the counsellor is never certain if the session they are conducting will be the last, but they can be a ‘constant profesional’.

Counselling in conjunction with other interventions such as individual assessments, information and support were found to delay institutionalisation (Olarzarin 2010). Pinquart and Sörensen (2006) found counselling had an effect on carer burden and CBT on carer burden and depression. Gallagher-Thompson and Coon (2007) found that psychotherapy interventions based on CBT and multi-component interventions which used a combination of at least two theoretical approaches such as individual counselling and support group participation were effective. Elvish et al's (2013) findings were consistent with Gallagher-Thompson and Coon in that interventions based on cognitive-behavioural models produced meaningful results for carers. Therapies that consisted of multiple components, such as individual and family counselling and support group participation were found to be beneficial.

The SuccessWorks (2011) project undertook action research to conduct a pilot to test four new ways of delivering counselling and support. These four projects were:

- online counselling
- online services for people with younger onset dementia
- a comparison of face-to-face and telephone counselling, and
- CALD best practice counselling

This report concluded that there was adequate evidence from the literature and action project findings in favour of these new modes of counselling. Staff participating in the focus groups also felt that making counselling available to a broader demographic through these different channels should be pursued and made available.

Education

Cooke *et al.* (2001) found that carers' knowledge of dementia could be improved by education, but this knowledge did not seem to have any influence on psychological or social outcomes. This supports the conclusion in the Department paper which states that carers are more satisfied with services that address psycho-social needs. Alzheimer's Australia education courses seek to address both the educational and psychological – and if possible will create the environment for social needs to be met in the future.

Carers who participated in the focus group described access to respite as a barrier to utilising education programs (where the education does not involve both as the Living with Dementia course does).

There was universal support expressed in the focus groups for education to be:

1. Active and targeted
2. Disease / disability specific
3. To be time relevant (to the caring experience) and provide a future orientation (even though the carer may not be seeking that information at that time)
4. Delivered in a variety of mediums including face-to-face, online, digital apps, tele-conference, MOOCs, web-conference etc.

Participants in the focus groups also pointed out that incidental and informal education of carers occurs through Awareness, Information, Intake, Needs Identification and Planning, Peer Support, Counselling and the components of the Multi-component intervention.

Peer Support

"It is up to us (carers) to avail ourselves of local dementia Carer's Groups. It is a long, hard journey, and it is good to share it with others. We are only human." Carer

Peer support can be either formal or informal in its structure. Not all people will want or need formal, structured processes. Conversely, informal structures may not be ideal either. It is important, therefore, to have a range of choices to meet the needs of carers. Peer support groups are important as they provide opportunities to speak to other people in a similar situation and provide social interaction, which is much needed.

Support groups began in the 1970's, emerging from the self-help movement and based on a mutual aid model of shared experience. As well as education there was an emphasis on support of a social nature (Brown and Tweedie, 2005). In the

1980's, Alzheimer's associations across Australia used this model to offer support to carers. These support groups provided a combination of mutual aid, dementia education and service information (Lovi and Tweedie, 2001 cited in Brown and Tweedie, 2005). At the end of the same decade two distinct types of support groups were emerging; mutual aid-based groups and groups offering psycho-educational interventions to address carers' psychological needs and provide coping skills (Brown and Tweedie 2005). These two types of support groups can be identified as follows:

- Mutual aid groups are open-ended with a leader who can be either a health professional or volunteer. They have social and educational aspects and an informal session structure.
- Psycho-educational groups are time limited - usually between 6 and 10 weeks, run by professionals with a structured framework and consist of skill training and other psycho-educational components.

Some groups use a combination of both approaches. (Brown and Tweedie 2005). Cooke *et al.* (2001) examined forty psychosocial interventions for carers to determine the impact they had on burden, psychological well-being and social outcomes. Their findings suggested that interventions with social components such as social support and those which combined social and cognitive components such as problem-solving, may be of benefit to carers' psychological well-being. In the review conducted by Pusey and Richards (2001), the "best" results came from interventions involving problem-solving and behaviour management.

Research into support groups was conducted in NSW between 2005 and 2009 by Brown and Tweedie (2005) and Brown (2007). It was found that the majority of these groups were of the mutual aid type. Feedback from carer participants indicated that support group attendance was a vital source of both emotional support and practical assistance. The initial motivation for carers to join a group was to obtain information about dementia and services, but mutual aid became the reason for carers' continued attendance. This research also found that the success of these groups was very much dependent on the group work skills of group leaders (Brown 2007). The research culminated in the production of the Best Practice Guidelines for Dementia Carer Support Group Leaders produced by AANSW in 2012. https://nsw.fightdementia.org.au/sites/default/files/20120802-NSW-PUB-BestPracticeGuideliensSupportGroups.pdf

An example of an ongoing mutual aid group type for both people with dementia and carers is the Dementia Cafe, also known as Memory or Alzheimer's cafes. Cafes were first established in the Netherlands in 1997 by Dr Bere Miesen to provide a relaxed atmosphere, embodied by the word "cafe", where those with dementia, carers and health professionals could talk about dementia and their experiences. In Meisen's view the Cafes have three main aims: to provide information about medical and psychosocial aspects of dementia; encourage speaking openly and the acceptance that goes with this and; assist people with dementia and their carers to be less isolated and make social connections (Miesen and Blom, 2001). Alzheimer's Australia NSW has just produced a Community Café Toolkit to assist people in the steps to establishing and successfully running a dementia café.

Alzheimer's Australia NSW research on the experience of moving into residential aged care highlighted the value of carer support group existence for carers whose role has changed to 'sharing the care'. They strongly identified as a carer, but acknowledged that their role was changing. The experience of peer support during this transition period was highly valued, but rarely found as most residential aged care providers do not organise or facilitate such groups.

At the focus group with carers, there was a discussion on informal mentoring and the value of peer-to-peer mentoring in helping carers. One attendee currently provides this service to others and finds it both valuable for her and for the carers she mentors. It was acknowledged that this is rare, worthy of further support and expansion, and potentially very valuable to carers.

Carers also were supportive of the expansion of peer support mediums e.g. telephone, web-conference, online forums, self-governing groups. However, they did query the reliability and efficacy of volunteer led groups over time. Given the reservations about volunteer led support mechanisms, they did question whether professional-led support may be more cost effective in terms of the outcomes produced.

A central feature of the literature on support groups is the concept of time. Carers needs change and evolve over time so what is needed and helpful at one point will not always remain so. Having a system navigator to support people through the system by signposting carers to services and support as their needs evolve would be valuable.

Multi-component intervention

The meta-analysis conducted by Brodaty *et al.* in 2003 of thirty interventions for carers found modest but significant benefits on carer knowledge, psychological distress, quality of life and other main outcomes (such as coping skills and social support) but not for carer burden. Those interventions that involved the person with dementia in a structured program with the carer were found to be more successful, with statistically significant results. Qualitative data showed that other important elements of interventions included: practical support for carers; involvement of other family members; structured individual counselling and; the availability of a professional who can consistently provide long term support. They concluded that some psychosocial interventions can reduce carer psychological distress and delay institutionalisation of the person with dementia. Programs that involve people with dementia and their families and are more intensive and adapted to carer's needs may be more successful.

Pinquart and Sörensen's (2006) review of 127 interventions found that carer interventions such as such as psycho-education, cognitive-behavioural therapy (CBT), counselling, support groups and respite could have small but significant effects on carer burden and depression and increase knowledge and well-being. Psycho-educational interventions that actively involved carers had the greatest effects. Multi-component interventions (which consisted of two or more interventions such as education, support and respite) had an effect on reducing the risk of institutionalisation. Two such examples are provided below

Brodaty and Gresham's study in 1989 recognised and addressed the relentless burden of dementia which can result is carers feeling "demoralised, isolated and psychologically distressed" (Brodaty and Gresham 1989:1375). Their study consisted of ninety-six carers and their person with dementia. Carers received intensive skills training whilst people with dementia participated in a number of activities including memory training. The program was held in a residential setting over 10 days. Teleconferences with carers were regularly held for twelve months post-program. The researchers followed up participants after the program ended at three, six and twelve months, then five and eight years later. It was found the intervention reduced carer stress and delayed residential placement for the person with dementia. Drawing on this study’s theoretical framework, HammondCare implemented a *Going to Stay at Home Program*.

Chien *et al. (2011)* recommended the length of intervention programs be at least 8 weeks – a modification that BaptistCare NSW & ACT applied to its Stronger Carers Program. The Stronger Carers program was a six- to ten-week individually tailored, in-home program for carers of people with dementia. With the support of their own Carer Coach, the program was designed for carers to develop knowledge and practical skills to confidently care for their family member with behavioural and psychological symptoms of dementia, whilst also learning stress management techniques to enhance their wellbeing and ability to care. The Stronger Carers program can be seen to be particularly successful in reducing carer depression, anxiety and stress, improving their self-efficacy and how carers perceive the changes to their lives as a result of caring. Carers also demonstrated that they had a better knowledge of services and support available to them and had accessed this support as a result of the program. Carers' knowledge of dementia in relation to the person they cared for increased as well as their skills in caring for them. They also reported that they coped better and were more able to deal with challenges. However, carers' survey responses indicated that they were less confident about other aspects of caring such as solving problems, being more in control, managing emotions and fatigue and finding balance in their lives. This is hardly surprising, given the difficult and constantly changing nature of caring for a person with dementia. A number of carers indicated that the program had assisted in the transition of their care recipient into residential care. Others indicated it had extended the time they were able to care for their care recipient at home. Alzheimer’s Australia

NSWs evaluation of Stronger Carers concluded that it is an innovative program, which successfully provided an individualised service for carers, by skilled and compassionate Carer Coaches. It is specifically tailored to individual carers' needs and provided on a one-to-one basis in the carer's home. The skills and abilities of the Carer Coaches and the fact that the program is delivered in an in-home format are probably the greatest contributors to its success.

The focus group participants were particularly concerned about the multi-component intervention as described in the discussion paper. As a principle statement, participants believe that carer should have choice and not be forced into this option. Further, staff questioned the evidence base that has informed the development of this service element. How were the three elements combined to comprise the multi-component intervention?

As stated previously, carers must have choices in the new program and it should not be overly prescriptive. A problem-solving, guided decision-making approach – not directed - has worked successfully in other programs delivered by Alzheimer's Australia NSW. Prescribing a multi-component intervention that reads like a 'take it or leave it' option is at odds with the philosophy of consumer control and choice. While it is conceded by carers in the focus group that they do not make perfect choices, that should not stop them from trying options and exercising freedom of choice.

Conclusion

Alzheimer's Australia NSW is largely supportive of the directions and principles outlined in the discussion paper and has provided the above comments to inform the development of this policy. Our research on what works and is cost effective for carers needs to work towards three outcomes: increasing mindfulness, resilience and self-efficacy. Attainment of these outcomes will ensure carers have an overall improved quality of life and caring experience, while also supporting the person with dementia to stay at home longer.