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Dementia Friendly Prisons - a mixed methods evaluation of the application of dementia friendly community principles to two prisons in England

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ABSTRACT

Objectives: To apply and evaluate dementia friendly community (DFC) principles in prisons.

Design: A pilot study and process evaluation using mixed methods, with a one-year follow-up evaluation period.

Setting: Two male prisons: a Category C sex offender prison (prison A), and a local prison (prison B).

Participants: 68 participants - 50 prisoners, 18 staff

Intervention: The delivery of dementia information sessions, and the formulation and implementation of dementia friendly prison action plans.

Measures: Study-specific questionnaires; Alzheimer's Society DFC criteria; semi-structured interview and focus group schedules.

Results: Both prisons hosted dementia information sessions which resulted in statistically significant ($p>0.05$) increases in attendees' dementia knowledge, which were sustained across the follow-up period. However, only prison A formulated and implemented a dementia action plan, which was mostly consistent with DFC criteria. Prison A participants reported some progress on awareness raising, environmental change and support to prisoners with dementia in maintaining their independence. The meeting of other dementia friendly aims was less apparent. Numbers of older prisoners, and those diagnosed with dementia appeared to have the greatest impact on engagement with dementia friendly community principles, as did the existence of specialist wings for older prisoners or those with additional care needs. Other barriers and facilitators were also reported within the

prison institution and environment, staff teams, prisoners, the prison culture and external factors.

Conclusions: DFC principles appear to be acceptable to prisons with some promising progress and results found. However, a lack of Government funding and strategy to focus action around the escalating numbers of older prisoners and those living with dementia appears to contribute to a context where interventions targeted at this highly vulnerable group can be deprioritised. A more robust evaluation of this intervention on a larger scale over a longer period of time would be useful to assess its utility further.

ARTICLE SUMMARY

Strengths and limitations of this study

- This is the first study published exploring the applicability of dementia friendly community principles in prisons that we have found, and is one of the only projects published worldwide to evaluate the support and/or management of prisoners living with dementia
- The PPI/E component of the study was invaluable in establishing the need for dementia-focused work, targeting the intervention and preparing study materials
- Involving people with dementia and their families in the intervention was particularly difficult to achieve in a prison context
- The relatively small sample size coupled with high prisoner and personnel turnovers made quantitative analysis challenging
- The number of participants interviewed and involved in focus group discussions provided a rich set of data to explore findings

KEYWORDS

Dementia, prisoner health, older prisoners, peer support, environment, awareness raising

INTRODUCTION

The numbers of prisoners over the age of 50[1] in England and Wales have tripled since 2002, and now represent 16.3% of the overall prison population.[1] This is projected to rise further in future.[2-3] Health problems and social care needs are reportedly extensive among this group, estimated to affect over 85% of older prisoners, with an approximately three-fold increase in costs.[4-8] The number of prisoners diagnosed with dementia specifically is unknown, but is at least commensurate with community levels, although likely to be much higher due to the poorer health and lifestyles of prisoners, and the effects of a prison system built for younger, fitter prisoners.[4-5, 9-12] Additionally, prisoners living with dementia [PLWDs] may have harsher prison experiences than their more cognitively able counterparts, which can exacerbate their symptoms, as they are more likely to be vulnerable to victimisation, isolation, and punishment for failing to 'comply' with prison routines.[5, 10, 13-17] It is a matter of national policy that prisons provide a standard of care equivalent to that in the community,[18-19] but a recent parliamentary inquiry has stated that despite some areas of good practice, the government is failing in its duty of care to prisoners in England and Wales.[20]

Dementia has become a health and social care policy priority in the UK, with the Governments' dementia strategy promoting the establishment of Dementia Friendly Communities [DFCs],[21-22] defined as places "where people with dementia are understood, respected and supported".[23, p1] Key DFC principles include: the empowerment and involvement of people with dementia, increased dementia awareness, challenging stigma, timely access to care, and supportive social and physical environments.[23] Evaluations of DFCs in UK communities mostly reported increases in

dementia awareness, but progress on social and environmental change varied and the involvement of people living with dementia were limited in the short-term.[24-30] There have been no published evaluations found applying DFC principles in prisons in England and Wales. Indeed, research focused on PLWDs appears to be extremely limited, with no published evaluations of interventions found anywhere in the world. Given the human rights and financial concerns surrounding the imprisonment of older prisoners and PLWDs,[16, 31-34] it seems imperative to explore, implement and evaluate programs focused on supporting this highly vulnerable population.

RESEARCH AIMS

This research project aimed to explore the application of the Alzheimer's Society Dementia Friendly Community principles to two diverse prisons. The research questions included:

1) What progress was made towards applying DFC principles at each prison?
2) What was the impact of implementation?
3) What contextual factors affected implementation?

METHOD

PROJECT DESIGN

The research was structured as a small-scale pilot study and process evaluation, employing a mixed methods design, with a one-year follow-up period. It was conducted in three stages:

(i) Patient and Public Involvement/Engagement [PPI/E] – established the need for dementia-related interventions at each prison, identified the people and site for

the intervention, and assisted in modifying evaluation materials. Prisoners were not directly involved in recruiting or conducting the evaluation, but findings were fed-back to prisoners through short reports and presentations where applicable.

(ii) Intervention – the delivery of hour-long Dementia Friends Alzheimer's Society information sessions (https://www.dementiafriends.org.uk/WEBRequestInfoSession), and meetings between prison staff and Alzheimer's Society representatives to plan and implement DFC-led alterations.

(iii) Evaluation – of the information session, of progress towards implementing DFC principles, and of contextual factors affecting their application.

PROJECT CONTEXT

This study was conducted in two prisons in the East of England. Prison A was a Category C sex offender prison with 34.2% of the population aged over 50,[35] and two opt-in 120 bed wings for older prisoners (aged >60 years). Prison B was predominantly a local prison[2] with 16.1% of the population over 50,[36] with a 26-bed wing for older prisoners, and a 15-bed palliative and significant social care needs wing. This prison also had 24-hour healthcare staff and an inpatient wing.

PARTICIPANTS

46 prisoners were involved in the PPI/E phase of the project. 45 prisoners and staff attended information sessions, all of whom were invited to participate by prison staff. 68 prisoners,

AS representatives and staff also took part in the evaluation either directly invited by researchers (for those who had previously consented to contact at the information session) or prison staff. Recruitment to all phases of the study was aimed at individuals most likely to be involved in supporting PLWDs and included: older prisoners, prisoner peer supporters and, staff working on specialist (older prisoner or health-oriented) wings. One PLWD participated in PPI/E at Prison A, although none were involved in the evaluation.

For the follow-up interviews and focus groups, information session attendees and staff who had been involved in planning and implementing DFC principles were invited to participate. The numbers of information sessions attendees reduced substantially across this period, therefore other prisoner peer supporters and prison officers who were interested in dementia at the prisons were also invited by prison staff to participate. For the follow-up evaluation, all staff participants were interviewed. Prisoners were selected for interview based on the type of peer supporter role they occupied – a representative of each role was chosen, and the remaining prisoners participated in focus groups.

MATERIALS

Information sheets and consent forms were developed by the research team and modified according to National Offender Management Service [NOMS] specification. The rest of the materials used included:

(a) Alzheimer's Society Foundation Criteria for the Dementia-Friendly Communities Recognition Process[37}

(b) Socio-demographic questionnaire

(c) A study-specific Information Session Evaluation questionnaire with open and closed questions on knowledge, learning and confidence regarding dementia

(d) Study-specific Dementia Friendly Prisons evaluation questionnaire based on the key DFC principles[23]

(e) The 'Dementia Friendly Physical Environments Checklist'[38]

(f) Semi-structured interview schedules and focus group frameworks focused on the information session, support and barriers for PLWDs, and prison dementia friendliness

PROCEDURES

The three steps taken in this project – PPI/E, Intervention and Evaluation – and their sequencing are shown in Figure 1:

<Figure 1: Project procedure>

Both prisons facilitated PPI/E activities, then hosted dementia information sessions, and had initial meetings with AS representatives, but only Prison A created and implemented DFC plans. Both Prison A and B participated in evaluation activities. A six-month interim follow-up occurred at Prison A due to rapidly falling numbers of information session attendees, and a full one-year follow-up was conducted at both prisons. At both follow-up points, prisoner interviews were taped during legal visits, focus groups within the prison were scribed and staff interviews were taped at suitable locations within and outside of the prison. Informed consent was sought from all follow-up participants prior to interviews or focus groups.

DATA ANALYSIS

Quantitative analysis

The data from the questionnaires were analysed using SPSS version 23. The data were analysed using either a Chi-squared, McNemar, or Wilcoxan signed-rank test. Statistical analysis focused on changes pre- and post-session and at follow-up.

Qualitative analysis

All taped interviews were transcribed verbatim which together with focus group flipcharts, were subject to a Framework Analysis[39]. This approach was selected as it could accommodate differing data sources, and provided a clear and systematic structure for a team-based analysis. Using an inductive approach, all researchers: (i) read interviews and noted initial themes; (ii) analysed five transcripts in-depth, noting further themes; (iii) based on this created an analytical framework with main emergent themes; (iv) used this framework to 'code' all material - two researchers independently categorised each transcript using NVivo 11 or MS Word; (v) analyses were combined and summarised in an MS Excel spreadsheet, with differences resolved within the team; and (vi) findings were interpreted.

RESULTS

PARTICIPANTS

A total of 68 individuals (50 prisoners and 18 staff) participated at different stages of this project, as shown in Figure 2:

<Figure 2: Flow of participants>

The project took place in two male prisons, with the majority of prisoners identifying as male (n=49, 98%), and one prisoner identifying as transgender. Conversely, the staff sample was mostly composed of females (n=11, 79%, missing =4). The mean age of the sample was 45.3 years, and ranged from 23-76 years (missing=8). The mean age of the prisoner participants from Prison A (50.6 years) was almost 10 years higher than the prisoner participants held at Prison B (40.9 years). This difference was statistically significant ($t(44)=2.793$, $p=0.008$). The overall mean age differences between prisons and between prisoners and staff were not statistically significant.

Of the 45 individuals who attended information sessions, 12 were followed up at six-months from Prison A, and seven from both prisons were followed up at one-year, although only two of these were followed-up at both six-months and one-year. 23 people participated in the follow-up stages of the evaluation who had not attended information sessions, largely at one-year (n=21). Across the follow-up evaluation, 19 interviews were conducted with prison staff (n=11), prisoners (n=6) and AS representative (n=2). A further 24 prisoners participated in focus groups.

KEY FINDINGS

This section will discuss the three research questions on progress, impact and context that this project sought to answer, and present an analysis of each.

RESEARCH QUESTION 1: PROGRESS

Both prisons agreed to participate and engaged in the project and evaluation, but they differed in the extent of their engagement. Progress was measured against Alzheimer's Society criteria,[37] which is summarised in Table 1 for each prison.

<Table 1 here>

Prison A met a number of the criteria which included joining a local Dementia Action Alliance[3], creating a DFC plan which was posted on the internet, running awareness raising events, and making small environmental changes. Actions in these areas were reportedly ongoing, although mostly were being implemented within the older prisoner wings. Progress was also reported to be slow:

> *"I feel I've been so lucky to be involved in this project…it's one of the few places that I've been where they've actually listened... and it's slow, but it's going to be slow, you just have to accept that. But, they do listen, and every time I go …something has happened in relation to what I've talked about previously. And that is so unique" (Prison project worker).*

Table 1: Progress as measured against Alzheimer's Society Foundation Criteria (2014)

CRITERIA	PRISON A	PRISON B
1. Create or join a Dementia Action Alliance (DAA)	(i)Joined the local DAA, attended regularly by prison staff (ii)Prison-only steering group not set up	The prison did not join nor create a DAA or similar
2. Identify a community leader	There was a lead person liaising with the AS rep throughout. This changed several times across the study	The identified lead met with the AS rep once, but a dementia friendly community was not worked towards.
3. Have an awareness raising plan	(i)Information sessions delivered largely to prisoner peer supporters as part of this research; AS rep delivered further session at a prisoner conference (ii) Two staff members trained as dementia champions enabling them to deliver awareness sessions (iii)Information session placed on staff training rotation, delivered by a staff dementia champion (iv) Awareness raising was a part of the prison action plan	(i)Information sessions delivered to prisoner peer supporters, and some healthcare and prison staff as part of the research (ii) No known ongoing plan to raise dementia awareness at the prison, and no further information sessions delivered
4. Involvement of people living with dementia, and their carers	(i)Prisoner peer supporters were asked for opinions, but project was staff led primarily (ii) Little formal contact between AS rep and prisoners (iii) No known involvement of family or friends of PLWDs	Prison not working towards establishing a dementia friendly community within this project, so no prisoner nor family or friends involved.
5. Publicise the work of the community	(i)The dementia action plan was posted on the DAA website (ii) The AS rep was a speaker at a prison-wide conference for prisoner peer supporters (iii) Staff working outside of specialist wings appeared unaware of the project	(i)There was no dementia friendly community plan (ii) A prisoner who attended the information session as part of this research, used the information to create an edition of the in-house prisoner magazine focused on dementia
6. Focus the action plans on two or three key priorities	A dementia action plan was created focused on: raising awareness; improving the physical environment; and working with partners inside and outside the prison	No dementia action plan was created
7. Have a 6-month and annual evaluation plan	(i)The prison participated in the research evaluation. The prison was continuing to work with AS and DAA, but unclear about ongoing plans to evaluate	The prison participated in the research evaluation – no further evaluation plans

Whilst Prison B engaged with some of the initial project-related activities (hosting information sessions and an initial meeting with an AS representative), there was little progress beyond this, with few AS criteria met and no DFC plans created. A prisoner at Prison B did use the information session materials to produce an edition of the prisoner magazine focused on dementia, and the difficulty of being in prison when family members are experiencing dementia or supporting others with dementia.

RESEARCH QUESTION 2: IMPACT

Within this study, impact was assessed using study specific questionnaires evaluating (i) the dementia information session delivered at both prisons, (ii) whether DFC aims were met, and if changes were made by the prison to support these. As no DFC plans were made or implemented at Prison B, analysis of this questionnaire will only be presented for Prison A. Quantitative results will also be augmented by interview and focus group analyses.

(a) Information session evaluation

Participants completed questionnaires evaluating the information session pre- (n=45) and post-session (n=40), and at six-months (n=12) and one-year follow-up (n=7). This was also explored further in interviews and focus groups. Table 2 shows data taken from the questionnaires across the evaluation period:

<Table 2 here>

Table 2: Descriptive statistics and comparative analyses of awareness session questionnaires

	PRE-COMPARISON ANALYSIS			POST-COMPARISON ANALYSIS		FOLLOW-UP ANALYSIS
	Pre-Post (n=38)	**Pre - 6-mth (n=12)**	**Pre - 1-year (n=7)**	**Post - 6 mth (n=11)**	**Post - 1-year (n=5)**	**6-mth – 1 year (n=3)**
Do you know what dementia is? *(N° Yes, %; significance level)**	31(86.1)-36(100) p=0.063 *2 missing*	n/a	n/a	n/a	n/a	n/a
How much do you know about dementia? *(median; significance/level)***	4 - 7 Z=-4.594, p<0.001 *1 missing*	5 - 6 Z=-2.831, p= 0.005	5 - 6 Z=-2.232, p=0.026	7 - 6 Z=-1.311, p=0.190	7 – 4 Z=0, p=1.000 *1 missing*	6 -4 Z=-1.414, p=0.157
Do you know the causes of dementia? *(N° Yes, %; Significance level)**	7(25) – 24(85.7) p<0.001 *10 missing*	n/a	n/a	n/a	n/a	n/a
Do you know what a dementia friendly community is? *(N° Yes, %; Significance level)**	13(44.8)-26(89.7) p<0.001 *9 missing*	7(70.0) - 9(90.0) p=0.500 *2 missing*	1(16.7) – 5 (83.3) p=0.125 *1 missing*	9(90.0) – 8(80.0) p=1.000 *1 missing*	3(100) – 3(100) p=1.000 *2 missing*	3(100)– 3(100) p=1.000
Did the awareness session increase your knowledge/did you learn? *(No, %; Significance level)**	n/a	n/a	n/a	10 (100)– 9 (90.0) p=1.000 *1 missing*	4 – 4 (100) p=1.000 *1 missing*	3(100) – 3 (100) p=1.000
Confidence in talking about dementia to others? *(median; significance/level)***	5 – 7 Z=-3.917, p<0.001 *8 missing*	5 - 7 Z=-0.854, p=0.393	5 – 6 Z=-1.069, p=0.285 *3 missing*	7 - 7 Z=-1.897, p=0.058	7 - 6 Z=0, p=1.000 *1 missing*	7 - 6 Z=0, p=1.000
Confidence in helping people living with dementia? *(median; significance/level)***	n/a	n/a	n/a	n/a	n/a	8 – 7 Z=0, p=1.000
Did the awareness session change your views on people with dementia? *(N° Yes, %; Significance level)**	n/a	n/a	n/a	n/a	n/a	3 – 3 (100) p=1.000

*Significance testing using exact McNemar's test
**Significant testing using Wilcoxon signed-rank test

= statistically significant

All of the responses concerning perceived knowledge of dementia increased post-session, reaching statistical significance for level of knowledge about dementia, its causes and dementia friendly communities. Participants also reported feeling more confident talking to people with dementia post-awareness session. At 6-months and one-year follow-up, participants continued to report that they knew more about dementia than they had pre-awareness session, differences which were statistically significant. Unsurprisingly, no results were significant for the three participants sampled at both 6-months and 1-year follow-up.

At follow-up, most information session attendees interviewed reported their attendance positively, with the awareness session reportedly increasing their knowledge and understanding of dementia, which led to an increase in confidence in interacting with PLWDs for some:

> *"I'd never met anyone with dementia before I came into prison you see. I'd only just met X* [prisoner] *before I come to your group. I was a bit stand offish to him because I didn't really understand his illness… after going to your group, when I interacted with X with what I'd learned about his memory loss, it was a lot easier for me to understand him and I think for him to understand me" (Prisoner)*

Some participants also reported that the session altered the way they supported PLWDs, with a positive knock-on effect on those relationships. There were also reports of participants finding the information personally comforting and useful in supporting family, colleagues and community members caring for someone with dementia:

"For me it helped me mostly because my grandad suffers with dementia… for me [the information session] *put my mind at ease a lot with that and helped me. And I talked with my mum and my grandma about it a lot more because of that, because I felt a bit more confident having that knowledge" (Prisoner)*

(b) *Dementia Friendly Prison Aims*

Table 3 shows study participants' views on whether Prison A met DFC aims at 6 months (n=15) and 1-year follow-up (n=12), using the DFC aims questionnaire. These were largely independent samples, therefore a comparative analysis was not possible.

<Table 3 here: Dementia Friendly Prison Aims questionnaire table>

At both six-months and one-year follow-up, the majority of participants reported that PLWDs did not face stigma and discrimination and were supported to live independently at the prison. At 6-months, the latter was reported to have improved – the only area in which participants reported positive change across the study. It is possible that this endorsement of support for independence reflects the way prisons in general expect prisoners to function, but in addition, Prison A had adopted a policy of 'enablement' at their establishment, which appears to be compatible with this:

*"I'm forever saying 'enable', enable as much as possible. Encourage them to clean, encourage them to tidy their cell up… get them doing as much as possible. [*PLWD A*], for all the will in the world you couldn't take work away from him, he just wants to do it himself…we're never going to take that off him" (Prisoner)*

Table 3: Dementia Friendly Prison Aims and Changes made to Prison A

DEMENTIA FRIENDLY PRISON AIMS	SIX-MONTH FOLLOW-UP (n-15)								ONE-YEAR FOLLOW-UP (n=12)							
	Aims met?		Change over last 6 months						Aims met?		Change over the last 6 months					
			For better		*No change*		*For worse*				*For better*		*No change*		*For worse*	
	n	*%*	*N*	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*N*	*%*
Views of PLWDs are listened to	**5**	**33.3**	4	26.7	6	40	3	20	**3**	**25**	3	25	6	50	0	0
Good understanding of dementia amongst prison staff	**2**	**13.3**	2	13.3	10	66.7	2	13.3	**2**	**16.7**	2	16.7	4	33.3	2	16.7
Good understanding of dementia amongst prisoners	**5**	**33.3**	5	33.3	8	53.3	1	6.7	**2**	**16.7**	3	25	4	33.3	1	8.3
Accessible and appropriate prison activities for PLWDs	**4**	**26.7**	1	6.7	11	73.3	2	13.3	**3**	**25**	0	0	7	58.3	1	8.3
PLWDs are made to feel they can contribute to prison life	**4**	**26.7**	3	20	8	53.3	3	20	**3**	**25**	0	0	7	58.3	1	8.3
Staff pick up and act upon early signs of dementia	**2**	**13.3**	4	26.7	8	53.3	1	6.7	**2**	**16.7**	1	8.3	6	50	1	8.3
PLWDs can engage fully in prison life	**6**	**40.0**	4	26.7	8	53.3	1	6.7	**4**	**33.3**	1	8.3	7	58.3	0	0
PLWDS supported to live as independently as possible	**10**	**66.7**	**6**	**40**	**4**	**26.7**	**3**	**20**	**10**	**83.3**	**3**	**25**	**6**	**50**	**0**	**0**
The prison is easy to get around for PLWDs	**4**	**26.7**	1	6.7	8	53.3	3	20.0	**4**	**33.3**	0	0	7	58.3	1	8.3
PLWDs are respected	**4**	**26.7**	1	6.7	9	60	4	26.7	**5**	**41.7**	1	8.3	6	50	1	8.3
PLWDs face stigma and discrimination here	**4**	**26.7**	3	20.0	8	53.3	2	13.3	**4**	**33.3**	1	8.3	6	50	1	8.3

Regarding the other DFC aims, only around a third or less of participants agreed that they had been met. This included two foci of Prison A's DFC action plan: ease of navigation and understanding and identifying symptoms of dementia, particularly amongst staff. Whilst on the one hand this may represent a lack of observable progress in these areas, it may also reflect that the dementia-focused work at Prison A was largely implemented across two older prisoner wings rather than prison-wide. This was indicated by staff participants who worked on mainstream wings reporting that they were unaware of the DFC project, and also by prisoner observation:

> *"I think those that work specifically on* [older prisoner wings], *I think they're becoming more aware. But as the others, they got a very mixed bag. A very mixed bag" (Prisoner)*

RESEARCH QUESTION 3: CONTEXTUAL FACTORS

Both prisons described DFC principles as applicable in a prison setting, although they differed in the extent to which they engaged with the intervention, and in their 'dementia friendliness'. An analysis of staff and prisoner interviews and focus group discussion highlighted elements of the prison context which could act as barriers or facilitators to the implementation of DFC principles, were related to: (i) the institution and environment, (ii) staff, (iii) prisoners, (iv) prison culture (policies, practices and beliefs) and (v) external factors. These are depicted in Figure 3 with apposite quotations, and are discussed further below.

<Figure 3: Barrier and Facilitators>

(i) Institution and Environment

Prison budget cuts and bureaucracy were reported to impact engagement with DFC principles. Among staff, there was discussion about the need to balance resources available with the need for additional dementia input. The larger number of older prisoners and relative stability of the prisoner population at prison A justified greater engagement with the project (although this fluctuated according to numbers of prisoners with a dementia diagnosis). At prison B, staff shortages were a more prominent theme, and staff reported that the lower numbers of older prisoners and the amount of prisoner turnover could not justify continued engagement – mental health problems and substance misuse were clearer priorities. Staff leads at this prison also reported that they felt their support of PLWDs was good enough already.

Overall, staff and prisoner opinion of the dementia friendliness of both of the prisons was more mixed. Specialist wings were mostly considered more suitable for PLWDs than mainstream wings, being characterised as safer and less isolating, with more relaxed rules and routines including unlocking prisoners during the day, and greater on-wing activities including a cognitive stimulation group at Prison B – although these were considered too few for some. At prison A there were opportunities for prisoners to socialise off-wing and a prison-wide unlocked policy for prisoners, with some prison-wide older prisoner-focused activities at both prisons (such as additional gym and library access), although again these

were considered to be too few, and less accessible for those on one specialist wing at prison B. However, operation of these altered regimes and activities were reportedly affected by resource and staff shortages, and subject to restriction at both prisons.

The environments of the specialist wings had had some adaptations for older prisoners (for example, stair lifts, painted areas, and quiet spaces at Prison A, and a more normalised dining area at Prison B). These wings were also reportedly easier to navigate and more comfortable than mainstream wings. However, it was widely agreed that these wings fell short of dementia friendliness (for example, cell doors not wide enough for wheelchairs at prison A, and lack of stair lifts in one prison B specialist wing), as did the overall prison environments which were reportedly confusing to get around - a 'concrete city'.

(ii) Staff

There were mixed reports from prisoners and staff on prison- and healthcare staff support for PLWDs. Prison staff regularly working on specialist wings were described as more dementia aware and supportive of PLWDs, than staff working on mainstream wings. However, there were reports from some staff and prisoners, that staff who did not want to work on specialist wings sometimes acted their frustration out on prisoners when placed there.

The presence of 24-hour healthcare staff at prison B and the introduction of social care at prison A were considered a potential benefit to PLWDs – although there were no reports of social care working with PLWDs at either prison. There were mostly positive reports of healthcare staff at Prison A, and mental health, wellbeing and specialist wing staff at Prison B. However, there was some concern expressed about the more 'security' focused operation of the healthcare wing and staff at prison B which would not appear to be conducive to supporting PLWDs. Lead staff at prison B were unequivocally positive about all aspects of healthcare provision. In addition, some participants suggested that healthcare staff seemed reluctant to make dementia diagnoses – with reports of prisoners with dementia symptoms outstripping numbers diagnosed. As well as this affecting the treatment of individual prisoners, this would also impact prison decisions about engaging with dementia-related interventions, as numbers justify resources.

(iii) *Prisoners*

Participants reported that whilst the experiences of PLWDs at both prisons may vary, it was likely to be confusing or frightening. Prisoners providing care support for PLWDs (such as orderlies) were considered vital at Prison A – possibly as a result of less healthcare staff cover. Both prisons employed prisoner peer supporters in various capacities, although the numbers were seen as too few by most staff and prisoners, with training, support and guidance particularly around dementia mostly reported as inadequate, and a lack of formal contracts making the roles unclear at prison A. It is of note that healthcare professionals working alongside orderlies on one of the specialist wings at prison B, were reported as offering good informal support.

(iv) Prison Culture

There were a number of aspects of prison policy, practice and culture which appeared to be compatible with DFC principles. These included *safety, security and decency* as guiding operating goals*; equality* in the application of rules; *equivalence* of care and support between prisons and the community; and at Prison A e*nablement* – maximising the independence of PLWDs. However, it seemed that some of these were applied patchily or too rigidly at times to be supportive. For example, instances of prioritising *security* over healthcare (such as when hospital appointments are missed), an expectation that all prisoners conform to rules *equally* irrespective of cognitive capacity, an overestimation of prisoners' abilities leading to a lack of support rather than *enablement,* and lack of *decency* in not offering through-the-night continence care.

Other aspects of prison culture that could affect the management and support of PLWDs as well as the likelihood of prisoners seeking help reported by both staff and prisoners, included conflicts around how the *punishment* of prison was perceived*,* between being sent to prison as punishment or for punishment; perceptions of prisoners as *malingering* or *manipulative; a 'macho'* or *tough* culture*; bullying and exploitation (*although only a couple of instances were reported)*;* and *stigma* particularly around being old - possibly affecting prisoners choice to move to specialist accommodation and staff desire to work with this group. It is also of note that the unequal *power* relationships and hierarchical nature of prisons suffuses all of these cultural elements. For example, fear of censure reportedly

resulted in the reluctance of some prisoner peer supporters advocating for PLWDs, and for more junior staff to challenge practice.

(v) External Factors – family/friends and central government

There were a couple of examples of liaison between prison staff and family members (mostly when they were dying or had died), family visits facilitated in quiet spaces, and the involvement of a charity that facilitated family connections at both prisons. However, there appeared to be a lack of systematic prison practice to maintain links between family and PLWDs with reports of: some prisoners risking punishment to help PLWDs make telephone calls; no apparent mechanism for family and friends to report concerns, or to input to assessments or support; and no support for family members in coping with the difficulty of having a family member in prison and living with dementia.

Central governments' austerity-driven cuts were reported to impact the whole prison system in myriad ways, some of which have already been documented. In addition, the lack of policy and strategy attention for PLWDs affects the amount to which prisons struggling with implementing mandatory operations and training can attend to that which is not mandated. This can render the status of additional dementia input as optional, or a "luxury" (Staff).

DISCUSSION

Summary of results

Both of the participating prisons reported that DFC principles were applicable to them, but differed in the extent to which they engaged with the intervention. Dementia information sessions were delivered at both, and reportedly increased participants' knowledge, confidence, and understanding of dementia, consistent with community DFC evaluations.[24-30] Prison A created and implemented a DFC action plan, facilitated additional awareness raising initiatives, small environmental changes, and reportedly helped PLWDs to live more independently – but, progress was considered slow and partial, and was mostly focused on older prisoner wings. Prison B did not create nor implement a DFC action plan. Facilitators and barriers for the implementation of DFC principles within a prison context largely flowed from where PLWDs chose to reside, with older prisoner-focused wings considered more dementia friendly, with more aware staff and prisoner peer supporters. Austerity-related cuts to prison budgets presented one of the biggest barriers to implementation and to decisions to engage in the intervention – which was also driven by numbers of older prisoners and PLWDs. Aspects of the prison culture appeared to have the potential to both support and undermine interventions focused on PLWDs.

Study strengths and limitations

Study strengths and limitations divide into those related to the fidelity of the intervention at Prison A, and those related to the running of the evaluation at both prisons.

Intervention

Although most of the AS intervention criteria were met, one of the key DFC principles proved challenging: involving PLWDs (although this was also a difficulty for community interventions).[24-30] Within this study, this was mostly due to fluctuating numbers of prisoners formally diagnosed with dementia, which also affected the evaluation. Additionally, DFC plans were largely created by the prison lead alone, but a steering group including PLWDs and their supporters including family members, as well as staff from across the prison, could help to establish and maintain a prison DFC more consistent with Alzheimer's Society central tenets. The Alzheimer's Society did not 'train' prisoners as Dementia Champions as part of this project. Overcoming bureaucratic obstacles to doing so within the organisation and the prison would also be more compatible with DFC principles.

Evaluation

This was the first published evaluation of the Government-endorsed DFC approach to prisons, and as a small-scale study was essentially exploratory. The PPI/E phase of the study proved valuable in targeting the work, and ensuring materials were workable, although an expanded role for prisoner involvement in design, recruitment and execution would have been desirable. The sample size for the information session evaluation was relatively small, and significantly reduced across the follow-up period affecting sub-group analyses, as did the lack of socio-demographic data. A 'traditional' one-year follow-up study of a prison-based intervention may be impossible on a small-scale due to prisoner and staff turnover – larger sample sizes, or briefer follow-up periods may be more feasible.

Implications and recommendations

The biggest challenge to the implementation of DFC principles in both prisons seemed to come from the significantly reduced budgets allocated since 2010, resulting in a quarter of the prison workforce being cut[40-41] and contributing to record levels of prisoner violence and self-harm.[42-45] As older prisoners typically pose less problems in these areas and reoffend less than their younger counterparts,[46-49] their difficulties are in danger of going unrecognised, underscored by the Government's repeated refusal to create a strategy focused on older prisoners.[16, 50-55]. In addition, the use of early release for prisoners is very limited. It is against this backdrop that a situation has emerged where interventions targeting prisoners with dementia, some of the most vulnerable prisoners in the system, can be described as unjustified rather than a moral, ethical and legal necessity. At present, it appears that it may only be prisons with very large numbers of older prisoners that can justify it.

Centralised resources and strategy are fundamental in the early release of PLWDs, in guiding and funding better health and social care coverage, and in creating more appropriate social and physical environments for PLWDs. However, there were a number of aspects of prison practice and policy identified more locally that could facilitate dementia friendly prison practice, some of which could be co-designed and delivered with external organisations:

- Partial segregation of older prisoners on specialist wings that are 'opt-in' for both prisoners and staff, with opportunities to leave the wing to mix with other prisoners and access activities and services if desired, appears to be advantageous.[56-57] A

more comprehensive programme of on-wing activities and groups, such as cognitive stimulation and reminiscence groups, and the adoption of an enablement ethos with specialist training and supervision for both wing staff and prisoner peer supporters (with formal contracts) may also be helpful[54].

- Dementia information sessions to be made available to the wider prison population via prisoner forums and rep meetings and placed on the staff training rotation, or delivered in chunks around officer schedules (such as at registration). These could include a reflection of the impact of the prison and its culture on PLWDs, and examples of good prison dementia practice derived from the work of prisoners and staff on the specialist wings and delivered by staff or prisoner Dementia Champions.
- Policies for older prisoners and those with disabilities (including PLWDs) across prisons which allow them to be unlocked through the day, paid a wage commensurate with their working peers, and access to appropriate activities – this could be through attendance at a centre for groups and activities.
- A focus on improving environments by making use of in-house expertise, labour, and adapting simple DFC design.[58-60]
- Access to specialist dementia training and support for healthcare staff where needed, with a clear referral pathway to specialist dementia services in the community. Also, as dementia has been linked to a number of other health issues such as depression, high blood pressure, smoking, poor nutrition and physical and social inactivity, dementia awareness could be included as part of broader health and social wellbeing promotion activities at prisons, including those with lower numbers of older prisoners.

- Review and translate local policies, practices and procedures for older prisoners, including disciplinary procedures regarding PLWDs. For example, decency (how to care for incontinence through the night) and safety (appropriate use of control and restraint techniques for older people). These could be disseminated through staff training sessions which could also challenge more problematic aspects of prison culture as it pertains to PLWDs, including age-related stigma, bullying, and malingering assumptions which has also been linked to prison suicide.[61]
- To systematically support the links between PLWDs and family more in line with NICE guidelines [62] prisons (with external partners) could: assist telephone calls, facilitate visits in quiet spaces, support older visitors with difficulty travelling, increase liaison between family/friends and the prison regarding reporting concerns and in the assessment and support of PLWDs, and support family and friends in coping with the distress of having a loved one in prison with dementia.

Future research

This was a pilot study that produced some promising findings, which warrants further investigation, such as a more robust evaluation with a larger sample size, across a variety of prisons, for longer periods. Exploring the intersectionality of other protected characteristics (for example gender and ethnicity) with age and dementia, will be particularly important to ensure the community is applicable for all.

The role of prisoner peer supporters for PLWDs appeared to be key in this study, and as to date there have been no published evaluations of their work, additional study would be valuable.[63] There is a particular lack of research focused on PLWDs worldwide, so further research on their experiences whilst in prison and upon resettlement in the community, thought to be particularly challenging[64], and the best ways to support them, would likely be useful to prison practitioners, researchers and policy makers.

FOOTNOTES

[1] *The age cut-off for 'older prisoner' varies, but is typically thought to be 10 years younger than the general population, as prisoners have been reported to age more rapidly due to lifestyle, healthcare access, substance misuse, and the stress of imprisonment (see [65] for further discussion)*

[2] *Local prisons serve the courts local to the prison, holding prisoners on remand, those serving shorter sentences and those serving longer sentences awaiting allocation to another prison.*

[3] *Organisations join local Dementia Action Alliances to "share best practice and take action on dementia" [66]*

[4]*anonymised to preserve confidentiality*

AUTHOR CONTRIBUTIONS

Samantha Treacy – design of study materials; facilitated focus groups and conducted interviews; led qualitative analysis, and conducted quantitative analyses; drafted the manuscript as lead author.

Anna Haggith – involvement with project conception and design; liaison with project partners; co-designed study materials; facilitated PPI/E, awareness sessions, interviews and focus groups; conducted qualitative analysis; contributed comments to manuscript drafts.

Nuwan Darshana Wickramasinghe – conducted quantitative analysis and qualitative analyses; edits to manuscript drafts.

Tine Van Bortel – Principle Investigator: conceived of and designed the study and grant proposal; oversaw and advised on all aspects of the study; design of study materials; liaison with project partners; contributed comments and edits to manuscript drafts.

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DISCLAIMER

The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care, nor of Her Majesty's Prison and Probation Service.

COMPETING INTERESTS

None declared.

PATIENT CONSENT

Not required.

ETHICS APPROVAL

Ethical approval for the study was granted by Anglia Ruskin University, with further permission obtained from the National Offender Management Service (NOMS), and the Governors of each participating prison.

PROVENANCE AND PEER REVIEW

Not commissioned, externally peer reviewed.

DATA SHARING STATEMENT

Additional data available on request from study authors.

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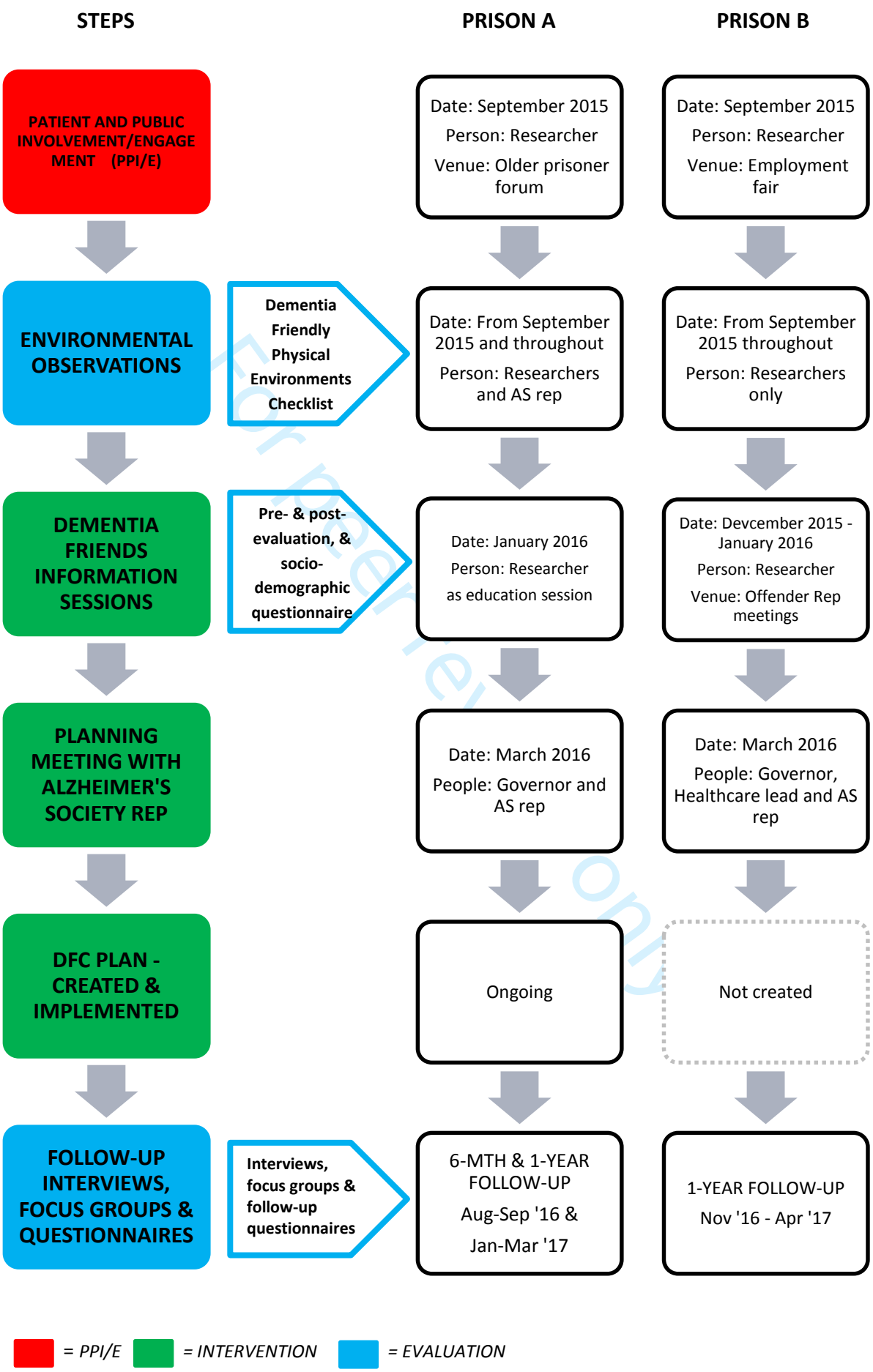

Figure 1: Steps involved in the implementation and evaluation of DFC principles

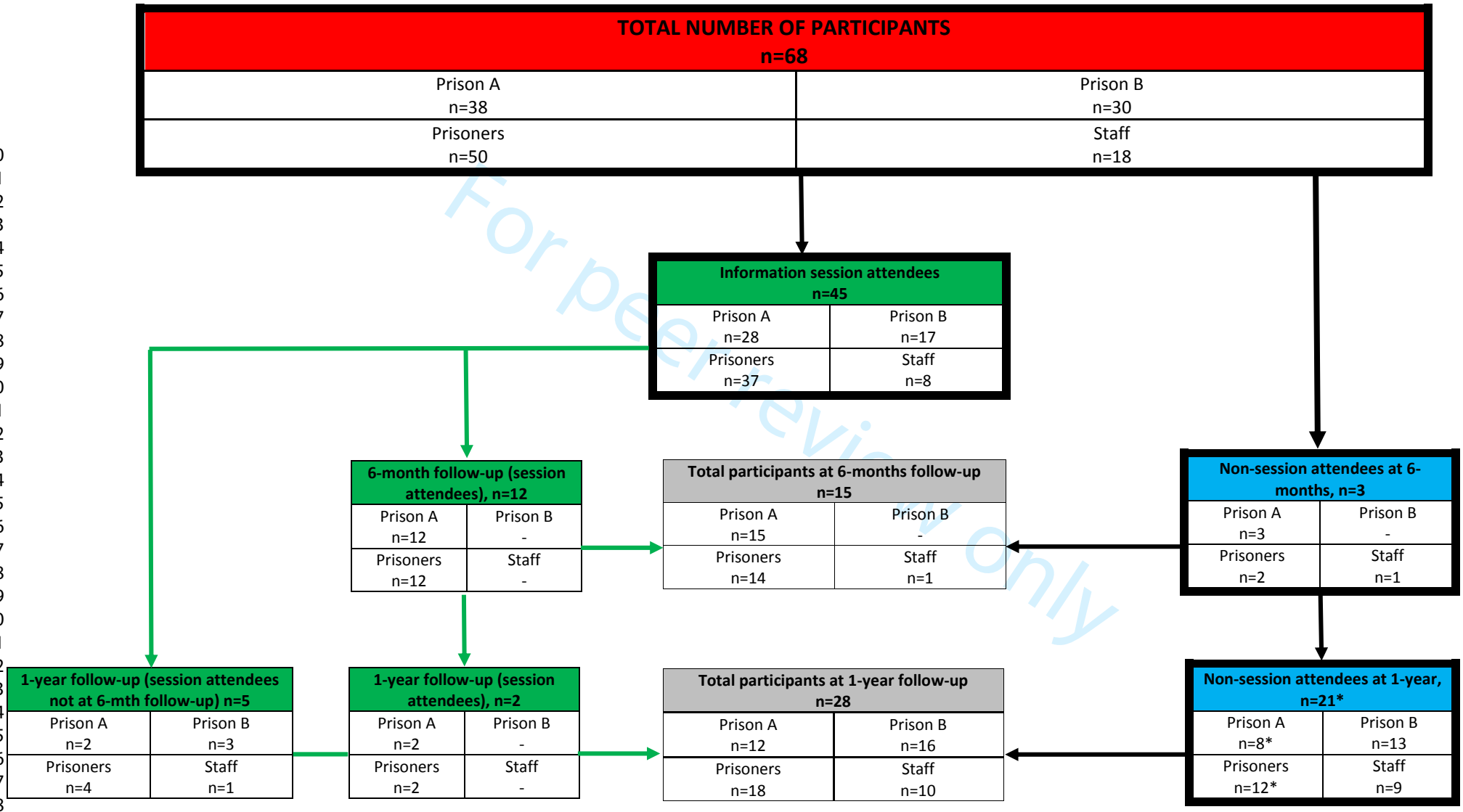

Figure 2: Flow of participants through the study

* One prisoner from Prison A did not attend the information session, but was involved at both 6-month and 1 year follow-up

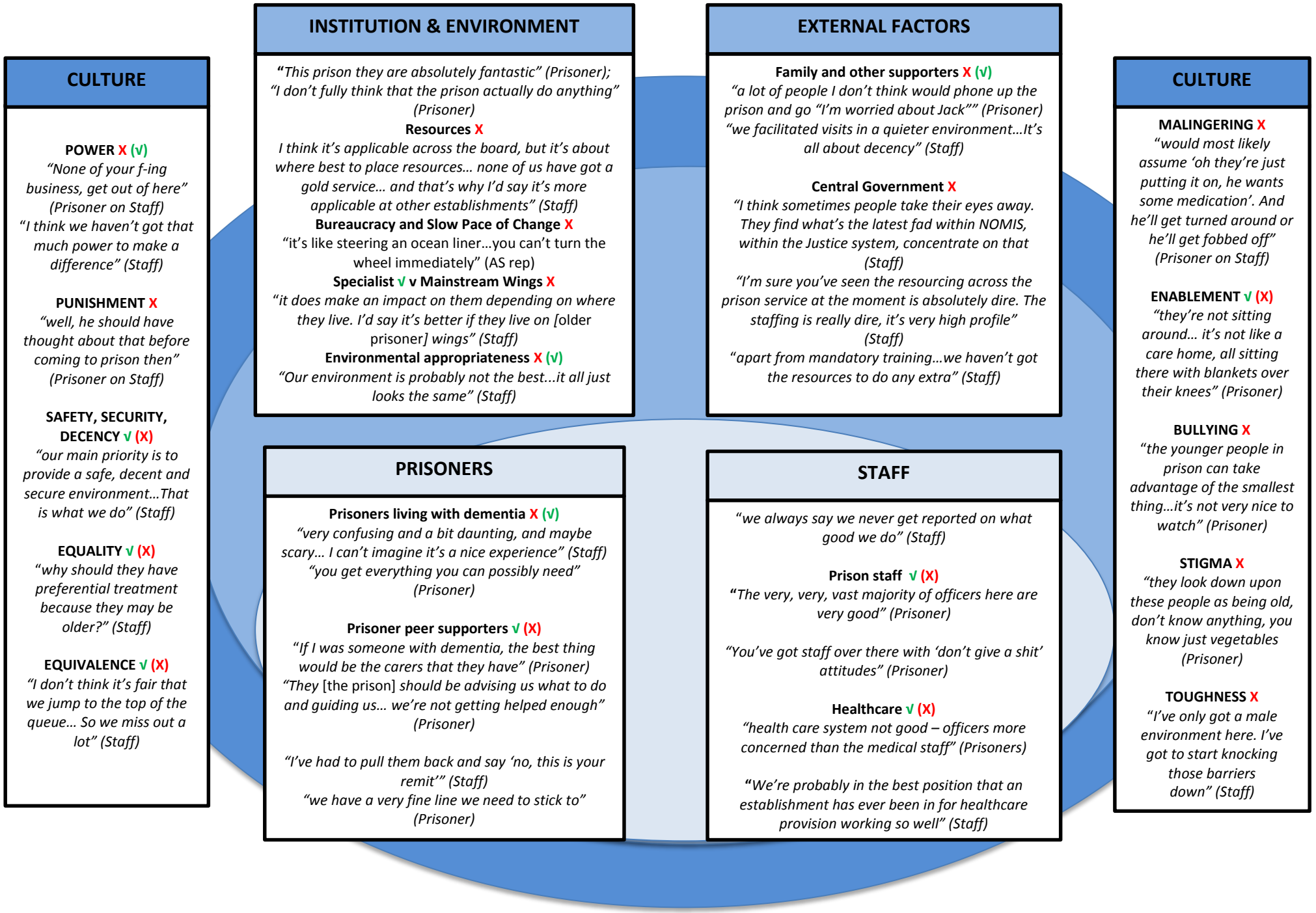

Figure 3: Barriers (x) and Facilitators (√) to applying Dementia Friendly Community principles, and their interactions

BMJ Open

Dementia Friendly Prisons - a mixed methods evaluation of the application of dementia friendly community principles to two prisons in England

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Dementia Friendly Prisons - a mixed methods evaluation of the application of dementia friendly community principles to two prisons in England

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ABSTRACT

Objectives: To apply and evaluate dementia friendly community (DFC) principles in prisons.

Design: A pilot study and process evaluation using mixed methods, with a one-year follow-up evaluation period.

Setting: Two male prisons: a Category C sex offender prison (prison A), and a local prison (prison B).

Participants: 68 participants - 50 prisoners, 18 staff

Intervention: The delivery of dementia information sessions, and the formulation and implementation of dementia friendly prison action plans.

Measures: Study-specific questionnaires; Alzheimer's Society DFC criteria; semi-structured interview and focus group schedules.

Results: Both prisons hosted dementia information sessions which resulted in statistically significant ($p>0.05$) increases in attendees' dementia knowledge, sustained across the follow-up period. Only prison A formulated and implemented a dementia action plan, although a Prison B prisoner dedicated the prisoner magazine to dementia, post-information session. Prison A participants reported some progress on awareness raising, environmental change and support to prisoners with dementia in maintaining independence. The meeting of other dementia friendly aims was less apparent. Numbers of older prisoners, and those diagnosed with dementia appeared to have the greatest impact on engagement with dementia friendly community principles, as did the existence of specialist wings for older prisoners or those with additional care needs. Other barriers and

facilitators included aspects of the prison institution and environment, staff teams, prisoners, prison culture and external factors.

Conclusions: DFC principles appear to be acceptable to prisons with some promising progress and results found. However, a lack of Government funding and strategy to focus action around the escalating numbers of older prisoners and those living with dementia appears to contribute to a context where interventions targeted at this highly vulnerable group can be deprioritised. A more robust evaluation of this intervention on a larger scale over a longer period of time would be useful to assess its utility further.

ARTICLE SUMMARY

Strengths and limitations of this study

- This is the first study published exploring the applicability of dementia friendly community principles in prisons that we have found, and is one of the only studies published worldwide to evaluate the support and/or management of prisoners living with dementia.
- The PPI/E component of the study was invaluable in establishing the need for dementia-focused work, targeting the intervention and preparing study materials
- Involving people with dementia and their families in the intervention was particularly difficult to achieve in a prison context.
- The relatively small sample size coupled with high prisoner and personnel turnovers made quantitative analysis challenging, and conducting the study in male prisons only is a limitation.
- The number of participants interviewed and involved in focus group discussions provided a rich set of data to explore findings.

KEYWORDS

Dementia, prisoner health, older prisoners, peer support, environment, awareness raising

INTRODUCTION

The number of prisoners over the age of 50[1] in England and Wales has tripled since 2002, and now represents 16.3% of the overall prison population.[1] This is projected to rise further in future.[2-3] Health problems and social care needs are reportedly extensive among this group, estimated to affect over 85% of older prisoners, which has been associated with an approximately three-fold increase in the financial costs of accommodating them compared to the 'general' prisoner population.[4-8] The number of prisoners diagnosed with dementia specifically is unknown, but is at least commensurate with community levels, although likely to be much higher due to the poorer health and lifestyles of prisoners, and the effects of a prison system built for younger, fitter prisoners.[4-5, 9-12] Additionally, people living with dementia in prisons may have harsher prison experiences than their more cognitively able counterparts, which can exacerbate their symptoms, as they are more likely to be vulnerable to victimisation, isolation, and punishment for failing to 'comply' with prison routines.[5, 10, 13-17] It is a matter of national policy that prisons provide a standard of care equivalent to that in the community,[18-19] but a recent parliamentary inquiry has stated that despite some areas of good practice, the government is failing in its duty of care to prisoners in England and Wales.[20]

Dementia has become a health and social care policy priority in the UK, with the Governments' dementia strategy promoting the establishment of Dementia Friendly Communities [DFCs],[21-22] defined as places "where people with dementia are understood, respected and supported".[23, p1] Key DFC principles include: the empowerment and involvement of people with dementia in the formation and

development of communities, increased dementia awareness, challenging stigma, timely access to care, and supportive social and physical environments.[23] Evaluations of DFCs in UK communities mostly reported increases in dementia awareness, but progress on social and environmental change varied and the involvement of people living with dementia were limited in the short-term.[24-30] There have been no published evaluations that we have found applying DFC principles in prisons in England and Wales, nor of any other intervention targeted at people living with dementia in prisons internationally.[31,32] Given the human rights and financial concerns surrounding the imprisonment of people with dementia,[12, 33-35] it seems imperative to explore, implement and evaluate programmes focused on supporting this highly vulnerable population.

RESEARCH AIMS

This study aimed to explore the application of the Alzheimer's Society Dementia Friendly Community principles to two prisons. The research questions were:

1) What progress was made towards applying DFC principles at each prison, following an intervention comprised of information sessions and meetings with the Alzheimer's Society?
2) What was the impact of the intervention?
3) What contextual factors affected implementation of the intervention and DFC principles?

METHOD

STUDY DESIGN

The research was structured as a small-scale pilot study and process evaluation, employing a mixed methods design, with a one-year follow-up period. It was conducted in three stages:

(i) PPI/E – established the need for dementia-related interventions at each prison, identified the people and site for the intervention, and assisted in modifying evaluation materials. Prisoners were not directly involved in recruiting or conducting the evaluation, but findings were fed-back to prisoners.

(ii) Intervention – delivery of hour-long Dementia Friends Alzheimer's Society [AS] information sessions (https://www.dementiafriends.org.uk/WEBRequestInfoSession), and meetings between prison staff and AS to plan and implement DFC-led alterations.

(iii) Evaluation – of the information session, of progress towards implementing DFC principles, and of contextual factors affecting their application, using questionnaires pre- and post-information session and at follow-up, and individual interviews and focus groups at follow-up.

The sequencing of these three stages across the study are shown in Figure 1:

<Figure 1: Study steps>

CONTEXT

This study was conducted in two prisons in the East of England. Prison A was a Category C sex offender prison with 34.2% of the population aged over 50,[36] and two opt-in 120 bed

wings for older prisoners (aged >60 years) which has had some adaptation (stair lifts, quiet room). There was also a prison-wide policy for older prisoners to be unlocked through the day. There were reportedly between zero and four prisoners diagnosed with dementia across the course of the study. Prison B was predominantly a local prison[2] with 16.1% of the population over 50,[37] and a 26-bed wing for older prisoners. In addition there was a 15-bed palliative and significant social care needs wing, with environmental adaptations (normalised dining area, hospital-type beds), which reportedly held five prisoners diagnosed with dementia at follow-up, and ran a cognitive stimulation group. This prison also had 24-hour healthcare staff and an inpatient wing. Both prisons had some prison-wide activities focused on older prisoners (such as dedicated gym/library sessions).

PARTICIPANTS

Forty-six prisoners were involved in the PPI/E phase of the study. A total of 68 individuals (50 prisoners and 18 staff) participated in the Intervention and Evaluation parts of the study, as shown in Figure 2:

<Figure 2: Flow of participants>

Forty-five prisoners and staff attended information sessions, invited by the staff who were leading for the study within each prison, as selected by each prisons' No 1 Governor. Invitations were extended to those likely to be involved in supporting people with dementia at the prisons and included: older prisoners, prisoner peer supporters and staff working on specialist (older prisoner or health-oriented) wings. Information session attendees were also asked for their consent to be approached to participate in the follow-up evaluation, and

were invited to do so by researchers and prison staff leads – with 12 people from prison A participating at 6-months, and a total of seven individuals from both prisons at 1-year follow-up. The remaining 23 follow-up evaluation participants were comprised of prison staff who led on or participated in the intervention implementation at the prisons (who were invited by the research team for interview), and of additional prisoner peer supporters and prison officers who were interested in dementia at the prisons (who were invited by the prison staff leads). One person with dementia participated in PPI/E at Prison A, but none were involved in the evaluation, as far as we were aware. The reasons for this are somewhat unclear, as the research team was not directly involved in recruiting prisoners.

Across the follow-up evaluation, 11 interviews were conducted with prison staff, and six with prisoners. A further 24 prisoners participated in focus groups. In addition, AS representatives (workers identified by AS to work with the prisons for this study) were interviewed, and were invited to do so by the researchers. Prisoners were selected for interview based on the type of peer supporter role they occupied, i.e. those providing direct care assistance to people with dementia (for example, care support orderlies, wheelchair pushers), those providing indirect assistance as a secondary part of their roles (such as library assistants), and prisoner representatives (who represent the views of prisoners at meetings with prison management). The remaining prisoners participated in focus groups.

MATERIALS

Information sheets and consent forms were developed by the research team and modified according to National Offender Management Service [NOMS] specification. The rest of the materials used included:

(a) Alzheimer's Society Foundation Criteria for the Dementia-Friendly Communities Recognition Process.[38]

(b) Socio-demographic questionnaire (gender, age, education level, marital status, race, children, religion, politics).

(c) Study-specific Information Session Evaluation questionnaire developed by the research team, and modified following prisoner feedback. The questionnaire contained open and closed questions on knowledge, learning and confidence regarding dementia. (see Supplementary File 1)

(d) Study-specific Dementia Friendly Prisons Aims questionnaire, developed by the research team, based on the key DFC principles.[23] (see Supplementary File 2)

(e) The 'Dementia Friendly Physical Environments Checklist'.[39]

(f) Semi-structured interview schedules and focus group frameworks formulated by the research team, focused on the information session, support and barriers for people with dementia, and prison dementia friendliness.

PROCEDURES

As shown in Figure 1, both prisons facilitated PPI/E activities, and hosted dementia information sessions at which pre- and post-session evaluation questionnaires were

collected. Due to sessions over-running, there were difficulties collecting the socio-demographic questionnaire at Prison A. Both prisons' study leads met with AS representatives, but only Prison A created and implemented DFC plans, at which a six-month interim follow-up occurred due to rapidly falling numbers of information session attendees. A full one-year follow-up was conducted at both prisons. At both follow-up points, evaluation and dementia aims questionnaires were collected, and interviews and focus groups conducted. Prisoner interviews were taped during legal visits, focus group discussions within the prison were documented on flip chart paper as permission to tape had not been sought in time, and staff interviews were taped at suitable locations within and outside of the prison, one was scribed by a researcher. Informed consent was sought from all participants prior to interviews or focus groups.

DATA ANALYSIS

Quantitative analysis

The data were extracted from the questionnaires by a researcher (ST) who was not involved in the intervention, and entered onto a dataset created using SPSS version 23.[40] One researcher (NDW), who was not involved in either the intervention or data collection, conducted an independent double-check to identify any incompatible entries. Both researchers (NDW, ST) analysed the data using SPSS. Statistical analysis focused on pre- and post-session and follow-up changes using Chi-squared, McNemar, or Wilcoxan signed-rank tests ($p<0.05$).

Qualitative analysis

All taped interviews were transcribed verbatim which together with focus group flipcharts, were subject to a Framework Analysis.[41] This approach was selected as it could accommodate differing data sources, and provided a clear and systematic structure for a team-based analysis. Using an inductive approach, all researchers: (i) read interviews and noted initial themes; (ii) analysed five transcripts in-depth, noting further themes; (iii) based on this created an analytical framework with main emergent themes; (iv) used this framework to 'code' all material - two researchers independently categorised each transcript using NVivo 11[42] or MS Word[43]; (v) analyses were combined and summarised in an MS Excel[44] spreadsheet, with differences resolved within the team; and (vi) findings were interpreted.

RESULTS

SAMPLE CHARACTERISTICS

A total of 68 individuals (50 prisoners and 18 staff) participated at different stages of this study. The majority of prisoners identified as male (n=49, 98%), and one prisoner identified as transgender. Conversely, the staff sample was mostly composed of females (n=11, 79%, missing =4). The mean age of the sample was 45.3 years, and ranged from 23-76 years (missing=8). The mean age of the prisoner participants from Prison A (50.6 years) was almost 10 years higher than the prisoner participants of Prison B (40.9 years). This difference was statistically significant ($t(44)=2.793$, $p=0.008$). The overall mean age differences between prisons and between prisoners and staff were not statistically

significant. With regards to the other socio-demographic variables, there were a large number of missing data making these difficult to interpret, however they have been included as Supplementary File 3.

KEY FINDINGS

This section will discuss the three research questions on progress, impact and context that this study sought to answer, and present an analysis of each.

RESEARCH QUESTION 1: PROGRESS

Both prisons agreed to participate and engaged in the project and evaluation, but they differed in the extent of their engagement. Progress was measured against Alzheimer's Society criteria,[38] which is summarised in Table 1 for each prison.

<Table 1 here>

Prison A met a number of the criteria which included joining a local Dementia Action Alliance[3], creating a DFC plan which was posted on the internet, running awareness raising events, and making small environmental changes. Actions in these areas were reportedly ongoing although slow, and mostly implemented within the older prisoner wings:

"I feel I've been so lucky to be involved in this project…it's one of the few places that I've been where they've actually listened... and it's slow, but it's going to be

Table 1: Progress as measured against Alzheimer's Society Foundation Criteria (2014)

CRITERIA	PRISON A	PRISON B
1. Create or join a Dementia Action Alliance (DAA)	(i)Joined the local DAA, attended regularly by prison staff (ii)Prison-only steering group not set up	The prison did not join nor create a DAA or similar
2. Identify a community leader	There was a lead person liaising with the AS rep throughout. This changed several times across the study	The identified lead met with the AS rep once, but a dementia friendly community was not worked towards.
3. Have an awareness raising plan	(i)Information sessions delivered largely to prisoner peer supporters as part of this research; AS rep delivered further session at a prisoner conference (ii) Two staff members trained as dementia champions enabling them to deliver awareness sessions (iii)Information session placed on staff training rotation, delivered by a staff dementia champion (iv) Awareness raising was a part of the prison action plan	(i)Information sessions delivered to prisoner peer supporters, and some healthcare and prison staff as part of the research (ii) No known ongoing plan to raise dementia awareness at the prison, and no further information sessions delivered
4. Involvement of people living with dementia, and their carers	(i)Prisoner peer supporters were asked for opinions, but project was staff led primarily (ii) Little formal contact between AS rep and prisoners (iii) No known involvement of family or friends of people with dementia	Prison not working towards establishing a dementia friendly community within this project, so no prisoner nor family or friends involved.
5. Publicise the work of the community	(i)The dementia action plan was posted on the DAA website (ii) The AS rep was a speaker at a prison-wide conference for prisoner peer supporters (iii) Staff working outside of specialist wings appeared unaware of the project	(i)There was no dementia friendly community plan (ii) A prisoner who attended the information session as part of this research, used the information to create an edition of the in-house prisoner magazine focused on dementia
6. Focus the action plans on two or three key priorities	A dementia action plan was created focused on: raising awareness; improving the physical environment; and working with partners inside and outside the prison	No dementia action plan was created
7. Have a 6-month and annual evaluation plan	(i)The prison participated in the research evaluation. The prison was continuing to work with AS and DAA, but unclear about ongoing plans to evaluate	The prison participated in the research evaluation – no further evaluation plans

slow, you just have to accept that. But, they do listen, and every time I go …something has happened in relation to what I've talked about previously. And that is so unique" (Prison project worker).

Whilst Prison B engaged with the intervention initially (hosting information sessions and meeting with an AS representative), there was little progress beyond this, with few AS criteria met and no DFC plans created. The lack of continued engagement largely centred around there being lower numbers of older prisoners at this prison, with other issues prioritised as a result, and the belief that services for people with dementia at the prison were good enough already. A prisoner at Prison B did use the information session materials to produce an edition of the prison magazine focused on dementia, and the difficulty of being in prison when family are experiencing dementia or supporting others with dementia.

RESEARCH QUESTION 2: IMPACT

Within this study, impact was assessed using study specific questionnaires evaluating (i) the dementia information session, and (ii) whether DFC aims were met, and if changes were made by the prison to support these. As no DFC plans were made or implemented at Prison B, analysis of questionnaire (ii) will only be presented for Prison A. Quantitative results will also be augmented by interview and focus group analyses.

(a) Information session evaluation

Participants completed questionnaires evaluating the information session pre- (n=45) and post-session (n=40), and at six-months (n=12) and one-year follow-up (n=7). This was also explored further in interviews and focus groups. Table 2 shows data taken from the questionnaires across the evaluation period:

<Table 2 here>

All of the responses concerning perceived knowledge of dementia increased post-session, reaching statistical significance for level of knowledge about dementia, its causes and dementia friendly communities. Participants also reported feeling more confident talking to people with dementia post-awareness session. At 6-months and one-year follow-up, participants continued to report that they knew more about dementia than they had pre-awareness session, differences which were statistically significant. Unsurprisingly, no results were significant for the three participants sampled at both 6-months and 1-year follow-up.

Some participants also reported that the session altered the way they supported people living with dementia in the prison, with a positive knock-on effect on those relationships. There were also reports of participants finding the information personally comforting and useful in supporting colleagues, and also extending to their communities of friends and family outside of prison:

"For me it helped me mostly because my grandad suffers with dementia… for me [the information session] *put my mind at ease a lot with that and helped me.*

Table 2: Descriptive statistics and comparative analyses of awareness session questionnaires

	PRE-COMPARISON ANALYSIS			POST-COMPARISON ANALYSIS		FOLLOW-UP ANALYSIS
	Pre-Post (n=38)	**Pre - 6-mth (n=12)**	**Pre - 1-year (n=7)**	**Post - 6 mth (n=11)**	**Post - 1-year (n=5)**	**6-mth – 1 year (n=3)**
Do you know what dementia is? *(N° Yes, %; significance level)**	31(86.1)-36(100) p=0.063 *2 missing*	n/a	n/a	n/a	n/a	n/a
How much do you know about dementia? *(median; significance/level)***	4 - 7 Z=-4.594, p<0.001 *1 missing*	5 - 6 Z=-2.831, p= 0.005	5 - 6 Z=-2.232, p=0.026	7 - 6 Z=-1.311, p=0.190	7 – 4 Z=0, p=1.000 *1 missing*	6 -4 Z=-1.414, p=0.157
Do you know the causes of dementia? *(N° Yes, %; Significance level)**	7(25) – 24(85.7) p<0.001 *10 missing*	n/a	n/a	n/a	n/a	n/a
Do you know what a dementia friendly community is? *(N° Yes, %; Significance level)**	13(44.8)-26(89.7) p<0.001 *9 missing*	7(70.0) - 9(90.0) p=0.500 *2 missing*	1(16.7) – 5 (83.3) p=0.125 *1 missing*	9(90.0) – 8(80.0) p=1.000 *1 missing*	3(100) – 3(100) p=1.000 *2 missing*	3(100)– 3(100) p=1.000
Did the awareness session increase your knowledge/did you learn? *(No, %; Significance level)**	n/a	n/a	n/a	10 (100)– 9 (90.0) p=1.000 *1 missing*	4 – 4 (100) p=1.000 *1 missing*	3(100) – 3 (100) p=1.000
Confidence in talking about dementia to others? *(median; significance/level)***	5 – 7 Z=-3.917, p<0.001 *8 missing*	5 - 7 Z=-0.854, p=0.393	5 – 6 Z=-1.069, p=0.285 *3 missing*	7 - 7 Z=-1.897, p=0.058	7 - 6 Z=0, p=1.000 *1 missing*	7 - 6 Z=0, p=1.000
Confidence in helping people living with dementia? *(median; significance/level)***	n/a	n/a	n/a	n/a	n/a	8 – 7 Z=0, p=1.000
Did the awareness session change your views on people with dementia? *(N° Yes, %; Significance level)**	n/a	n/a	n/a	n/a	n/a	3 – 3 (100) p=1.000

*Significance testing using exact McNemar's test
**Significant testing using Wilcoxon signed-rank test

= statistically significant

And I talked with my mum and my grandma about it a lot more because of that, because I felt a bit more confident having that knowledge" (Prisoner)

(b) *Dementia Friendly Prison Aims*

Table 3 shows study participants' views on whether Prison A met DFC aims at 6 months (n=15) and 1-year follow-up (n=12), using the DFC aims questionnaire. These were largely independent samples, therefore a comparative analysis was not possible.

<Table 3: Dementia Friendly Prison Aims questionnaire table>

At both six-months and one-year follow-up, the majority of participants reported that people with dementia in the prison did not face stigma and discrimination and were supported to live independently at the prison. At 6-months, the latter was reported to have improved – the only area in which participants reported positive change across the study. It is possible that this reflects that prisons in general expect prisoners to function independently within parameters, but in addition, Prison A had adopted a policy of 'enablement', which appears to be compatible with this DFC aim:

"*I'm forever saying 'enable', enable as much as possible. Encourage them to clean, encourage them to tidy their cell up… get them doing as much as possible. [Person* with dementia*], for all the will in the world you couldn't take work away*

Table 3: Dementia Friendly Prison Aims and Changes made to Prison A

DEMENTIA FRIENDLY PRISON AIMS	SIX-MONTH FOLLOW-UP (n-15)								ONE-YEAR FOLLOW-UP (n=12)							
	Aims met?		Change over last 6 months						Aims met?		Change over the last 6 months					
			For better		No change		For worse				For better		No change		For worse	
	n	*%*	*N*	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*N*	*%*
Views of people with dementia are listened to	**5**	**33.3**	4	26.7	6	40	3	20	**3**	**25**	3	25	6	50	0	0
Good understanding of dementia amongst prison staff	**2**	**13.3**	2	13.3	10	66.7	2	13.3	**2**	**16.7**	2	16.7	4	33.3	2	16.7
Good understanding of dementia amongst prisoners	**5**	**33.3**	5	33.3	8	53.3	1	6.7	**2**	**16.7**	3	25	4	33.3	1	8.3
Accessible and appropriate prison activities for people with dementia	**4**	**26.7**	1	6.7	11	73.3	2	13.3	**3**	**25**	0	0	7	58.3	1	8.3
People with dementia are made to feel they can contribute to prison life	**4**	**26.7**	3	20	8	53.3	3	20	**3**	**25**	0	0	7	58.3	1	8.3
Staff pick up and act upon early signs of dementia	**2**	**13.3**	4	26.7	8	53.3	1	6.7	**2**	**16.7**	1	8.3	6	50	1	8.3
People with dementia can engage fully in prison life	**6**	**40.0**	4	26.7	8	53.3	1	6.7	**4**	**33.3**	1	8.3	7	58.3	0	0
People with dementia supported to live as independently as possible	**10**	**66.7**	**6**	**40**	**4**	**26.7**	**3**	**20**	**10**	**83.3**	**3**	**25**	**6**	**50**	**0**	**0**
The prison is easy to get around for people with dementia	**4**	**26.7**	1	6.7	8	53.3	3	20.0	**4**	**33.3**	0	0	7	58.3	1	8.3
People with dementia are respected	**4**	**26.7**	1	6.7	9	60	4	26.7	**5**	**41.7**	1	8.3	6	50	1	8.3
People with dementia face stigma and discrimination here	**4**	**26.7**	3	20.0	8	53.3	2	13.3	**4**	**33.3**	1	8.3	6	50	1	8.3

from him, he just wants to do it himself…we're never going to take that off him" (Prisoner)

Regarding the other DFC aims, only around a third or less of participants agreed that they had been met. This included two foci of Prison A's DFC action plan: ease of navigation and understanding and identifying symptoms of dementia, particularly amongst staff. Whilst on the one hand this may represent a lack of observable progress in these areas, it may also reflect that the dementia-focused work at Prison A was largely implemented across two older prisoner wings rather than prison-wide. This was indicated by staff participants who worked on mainstream wings reporting that they were unaware of the DFC project, and also by prisoner observation:

"I think those that work specifically on [older prisoner wings], *I think they're becoming more aware. But as the others, they got a very mixed bag. A very mixed bag" (Prisoner)*

RESEARCH QUESTION 3: CONTEXTUAL FACTORS

An analysis of staff and prisoner interviews and focus group discussion identified elements of the prison context which could act as barriers or facilitators to the implementation of DFC principles. These were related to: (i) institution and environment, (ii) staff, (iii) prisoners, (iv) prison culture and (v) external factors. These are depicted in Figure 3 with apposite quotations, and are discussed further below.

<Figure 3: Barrier and Facilitators>

(i) Institution and Environment

Prison budget cuts and bureaucracy were reported to impact engagement with the intervention, and implementation. Staff reported that the larger number of older prisoners and relative stability of the prisoner population at prison A justified greater engagement with the project (although this fluctuated according to numbers of prisoners with a dementia diagnosis). At prison B, staff reported that the lower numbers of older prisoners and the amount of prisoner turnover could not justify continued engagement – mental health problems and substance misuse were clearer priorities. Staff leads at this prison also reported that they felt their support of people with dementia was good enough already.

Overall, staff and prisoner opinion of the dementia friendliness of both of the prisons was mixed. Specialist wings were largely considered more suitable for people with dementia than mainstream wings, as they were considered to be safer and less isolating, with more relaxed regimes and activities. Opportunities to socialise outside of the specialist wings at Prison A was considered positively, although some felt activities were too few at both prisons. Environmentally, the specialist wings were reportedly easier to navigate and more comfortable than mainstream wings. However, it was widely agreed that these fell short of dementia friendliness (for example, cell doors not wide enough for wheelchairs at prison A,

and lack of stair lifts at prison B), as did the prisons overall, which were reportedly difficult to get around. Relaxed regimes, activities and adaptations were all affected by budget cuts.

(ii) Staff

There were mixed reports from prisoners and staff on prison- and healthcare staff support for people with dementia in the prisons. Prison staff regularly working on specialist wings were described as more dementia aware and supportive of people with dementia, than staff working on mainstream wings. However, this more supportive practice seemed dependent on whether staff were able to choose this work. The introduction of social care at prison A and the presence of 24-hour healthcare staff at prison B were considered a potential benefit to people with dementia. There were mostly positive reports of most healthcare staff at both prisons, but there was some concern expressed about the more 'security' focused operation of the inpatient wing and staff at prison B. Some participants also suggested that healthcare staff seemed reluctant to make dementia diagnoses – with reports of prisoners with dementia symptoms outstripping numbers diagnosed, affecting treatment and also prison decisions to engage with dementia-related interventions.

(iii) *Prisoners*

Reports of the experiences of people with dementia at both prisons varied, but most participants suggested that it was likely to be confusing or frightening. Peer supporters providing direct care support for those with dementia were considered to provide vital support at Prison A – possibly as a result of less healthcare cover. The number of peer

supporters at both prisons were seen as too few by most participants, with training, support and guidance around dementia mostly reported as inadequate, and a lack of formal contracts making roles unclear at prison A. It is of note that healthcare staff were reported to offer peer supporters good informal support on one of the specialist wings at prison B.

(iv) Prison Culture

There were a number of aspects of prison policy, practice and culture which appeared to be compatible with DFC principles: *safety, security and decency* as guiding operating goals*;* *equality* in the application of rules; *equivalence* of care between prisons and the community; and at Prison A e*nablement*. However, it seemed that some of these were applied patchily or too rigidly at times to be supportive, such as an expectation that all prisoners conform to rules *equally* irrespective of cognitive capacity, or a lack of *decency* in not offering through-the-night incontinence care.

Other aspects of prison culture were identified that could affect the support of people with dementia, as well as the likelihood of prisoners seeking help. These included: how the *punishment* of prison was perceived - prison as punishment or prison for punishment; perceptions of prisoners as potentially *malingering* or *manipulative; a* somewhat *'macho'* culture*; bullying and exploitation* (although only a couple of instances were reported)*;* and *stigma* about age – which seemed to have some effect on prisoners' choice of accommodation and staff desire to work with this group. It is also of note that *power* relationships suffuse prison culture. Some manifestations of this reported were: fear of

censure resulting in the reluctance of some peer supporters to advocate for people with dementia in the prison, and for more junior prison staff to challenge practice.

(v) External Factors – family/friends and central government

There were a couple of examples of liaison between prison staff and family (mostly when prisoners were dying or had died), family visits facilitated in quiet spaces, and the involvement of a charity that facilitated family connections at both prisons. However, there appeared to be a lack of mechanisms/policy in place to maintain links between family/friends and people with dementia in both prisons, which included assistance with telephone calls, and for family to report concerns or receive support, and some reports of other prisoners risking punishment to assist.

Central governments' austerity-driven cuts were reported to impact the whole prison system in myriad ways. The lack of policy and strategy attention for people living with dementia appeared to amplify the effect. Given both prisons reportedly struggled with implementing mandatory operations and training, attending to issues that are not mandatory seemed to render the status of additional dementia input as a "luxury" (Staff).

DISCUSSION

Summary of results

Both of the participating prisons reported that DFC principles were applicable to them, but differed in the extent to which they engaged with the intervention. Dementia information

sessions were delivered at both, and reportedly increased participants' knowledge, confidence, and understanding of dementia, consistent with community DFC evaluations.[24-30] Prison A created and implemented a DFC action plan, facilitated additional awareness raising initiatives, small environmental changes, and reportedly helped people with dementia to live more independently – but, progress was considered slow and was mostly focused on older prisoner wings. Prison B did not create nor implement a DFC action plan. Facilitators and barriers for the implementation of DFC principles largely flowed from where individuals living with dementia chose to reside, with older prisoner-focused wings considered more dementia friendly, with more 'aware' staff and peer supporters. Austerity-related cuts to prison budgets presented one of the biggest barriers to implementation and to decisions to engage in the intervention – which was also driven by numbers of older prisoners and people with dementia diagnoses.

Study strengths and limitations

Study strengths and limitations divide into those related to the fidelity of the intervention at Prison A, and those related to the running of the evaluation at both prisons.

Intervention

Although most AS intervention criteria were met, one of the key DFC principles proved challenging: involving people with dementia (although this was also a difficulty for community interventions).[24-30] Within this study, this appeared to be partly due to fluctuating numbers of prisoners formally diagnosed with dementia, which also affected the

evaluation. Additionally, DFC plans were largely created by the prison lead alone, but a steering group including people with dementia in the prison, family, peer supporters, and staff from across the prison, could establish and maintain a prison DFC more consistent with AS's central tenets. The AS did not 'train' prisoners as Dementia Champions as part of this project. Overcoming bureaucratic obstacles to doing so would also be more compatible with DFC principles.

Evaluation

This is the first published evaluation of the Government-endorsed DFC approach to prisons, and – as a small-scale study – was essentially exploratory, taking place in only two prisons, and with no control groups. The PPI/E phase of the study proved valuable in targeting the work and ensuring materials were workable, although an expanded role for prisoner involvement in design, recruitment and execution would have been desirable. The sample size for the information session evaluation was relatively small, and significantly reduced across the follow-up period affecting sub-group analyses, as did the lack of socio-demographic data. A 'traditional' one-year follow-up study of a prison-based intervention may be impossible on a small-scale due to high prisoner and staff turnover – larger sample sizes, or briefer follow-up periods may be more feasible.

Implications and recommendations

The biggest challenge to the implementation of DFC principles in both prisons seemed to come from the significantly reduced budgets allocated since 2010, resulting in a quarter of the prison workforce being cut,[45-46] and contributing to record levels of prisoner violence

and self-harm.[47-50] As older prisoners typically pose less problems and reoffend less than their younger counterparts,[51-54] their difficulties are in danger of going unrecognised, underscored by the Government's repeated refusal to create a strategy focused on them.[16, 55-60] Centralised resources and strategy are fundamental in the early release of people living with dementia in prison, which is currently rarely used, in guiding and funding better health and social care, and more appropriate social and physical environments. However, there were a number of more locally-controlled practices that could facilitate DFC practice, some of which could be co-designed and delivered with external organisations:

- Partial segregation of older prisoners on wings that are 'opt-in' for both prisoners and staff, with trained and supported staff and peer supporters,[59] a comprehensive programme of activities, and opportunities for prisoners to leave the wing to access prison-wide activities and services if desired.[61-62]
- Dementia information sessions made available to the wider prison, to include a reflection of the impact of prison and its culture on people with dementia, and examples of good prison dementia practice from specialist wings or health/social care. Could be part of broader health promotion activities.
- Policies for older prisoners and those with dementia which allow them to be unlocked, to receive retirement pay commensurate with working peers' pay, and to access appropriate activities – potentially at an off-wing centre.
- Use of in-house expertise, labour, and adaption of simple DFC design to improve environments.[63-65]

- Access to specialist dementia training for healthcare staff where needed, and a clear referral pathway to specialist dementia services in the community. Dementia awareness could be included as part of broader health promotion activities.
- Review and translate local policies, practices and procedures for older prisoners and people with dementia, including disciplinary and restraint procedures, and resultant training can address more problematic aspects of prison culture, including stigma, bullying, and malingering assumptions – linked as they are to prison suicide.[66]
- To systematically support the links between people living with dementia in prison and their family to be more in line with NICE guidelines[67], for example, to assist telephone calls, facilitate travel to visits in quiet spaces, increase liaison between family/friends and the prison, and support family and friends in coping with the distress of having a loved one in prison with dementia.

Future research

This was a pilot study that produced some promising findings warranting further investigation, such as a more robust evaluation with a larger sample size, across a variety of prisons, for longer periods. Exploring the intersectionality of other protected characteristics (for example gender and ethnicity) with age and dementia, will be particularly important to ensure the community is applicable to all.

The role of prisoner peer supporters for people with dementia in prison appeared to be key in this study, and as to date there have been no published evaluations of their work,

additional study would be valuable.[68] There is a particular lack of research focused on people living with dementia in prisons and upon the challenges of resettlement[69], so further research on their experiences and the most effective ways to support them, would likely be useful to prison practitioners, researchers and policy makers.

CONCLUSION

In the two prisons involved in this pilot study and process evaluation, DFC principles were considered applicable, and information sessions reportedly positive, but only one prison continued to work with the Alzheimer's Society in creating and implementing DFC plans. A number of contextual factors appeared to impact both engagement with the study and also in dementia friendly practice in prisons in general. However, perhaps the most fundamental was the balancing of resources - having to make difficult decisions about whether the numbers of both older prisoners, and prisoners with dementia, were sufficiently high to justify engagement with non-compulsory dementia-focused interventions in a context of Government-sanctioned austerity and budget cuts. Without policy at Government-level to focus attention on one of the most vulnerable groups living in prison, it may only be prisons with very large numbers of older prisoners that can justify interventions targeting prisoners with dementia, which raises moral, legal and ethical concerns for those who do not.

FOOTNOTES

[1] *The age cut-off for 'older prisoner' varies, but is typically thought to be 10 years younger than the general population, as prisoners have been reported to age more rapidly due to lifestyle, healthcare access, substance misuse, and the stress of imprisonment (see [70] for further discussion)*

[2] *Local prisons serve the courts local to the prison, holding prisoners on remand, those serving shorter sentences and those serving longer sentences awaiting allocation to another prison.*

[3] *Organisations join local Dementia Action Alliances to "share best practice and take action on dementia" [71]*

[4]*anonymised to preserve confidentiality*

AUTHOR CONTRIBUTIONS

Samantha Treacy – design of study materials; facilitated focus groups and conducted interviews; led qualitative analysis, and conducted quantitative analyses; drafted the manuscript as lead author.

Anna Haggith – involvement with project conception and design; liaison with project partners; co-designed study materials; facilitated PPI/E, awareness sessions, interviews and focus groups; conducted qualitative analysis; contributed comments to manuscript drafts.

Nuwan Darshana Wickramasinghe – conducted quantitative analysis and qualitative analyses; edits to manuscript drafts.

Tine Van Bortel – Principle Investigator: conceived of and designed the study and grant proposal; oversaw and advised on all aspects of the study; design of study materials; liaison with project partners; contributed comments and edits to manuscript drafts.

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DISCLAIMER

The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care, nor of Her Majesty's Prison and Probation Service.

COMPETING INTERESTS

None declared.

PATIENT CONSENT

Not required.

ETHICS APPROVAL

Advice was sought from the Anglia Ruskin University ethics committee, and full ethical approval for the study was granted by the National Offender Management Service (NOMS) – National Research Committee, with further permission obtained from the Governors of each participating prison.

PROVENANCE AND PEER REVIEW

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DATA SHARING STATEMENT

Deidentified participant data are available from Orcid ID 0000-0003-0467-6393 upon request

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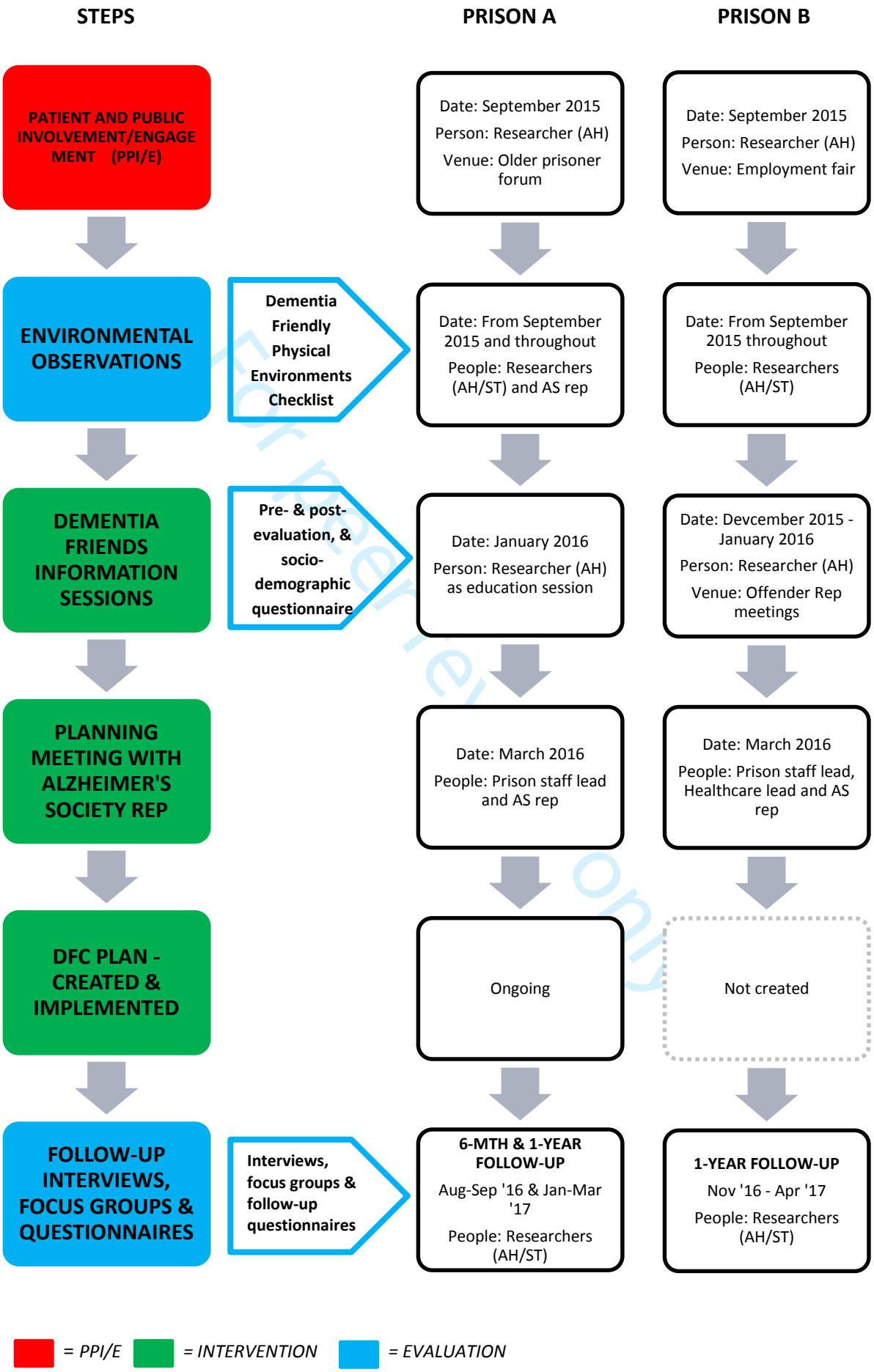

Figure 1: Steps involved in the study

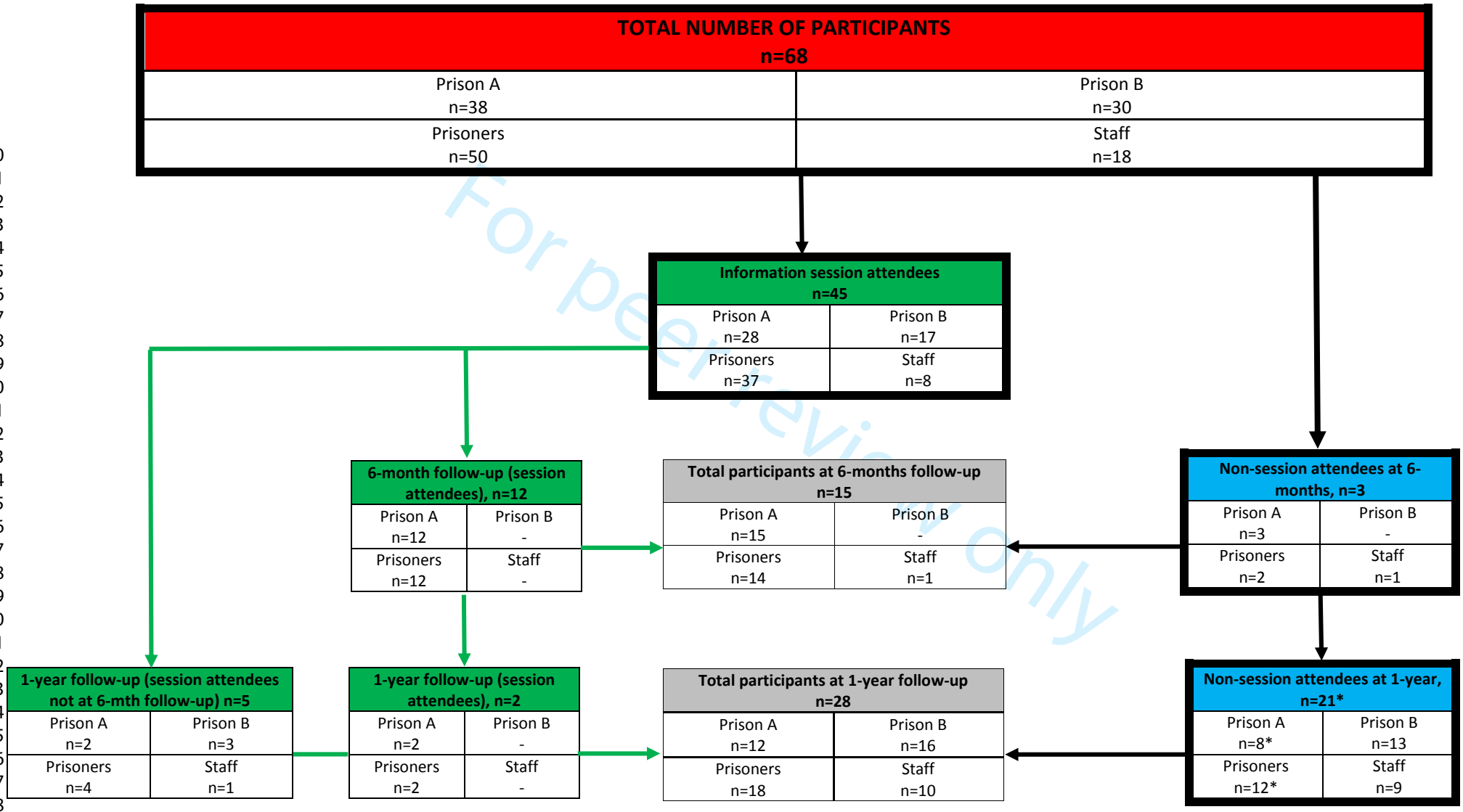

Figure 2: Flow of participants through the study

* One prisoner from Prison A did not attend the information session, but was involved at both 6-month and 1 year follow-up

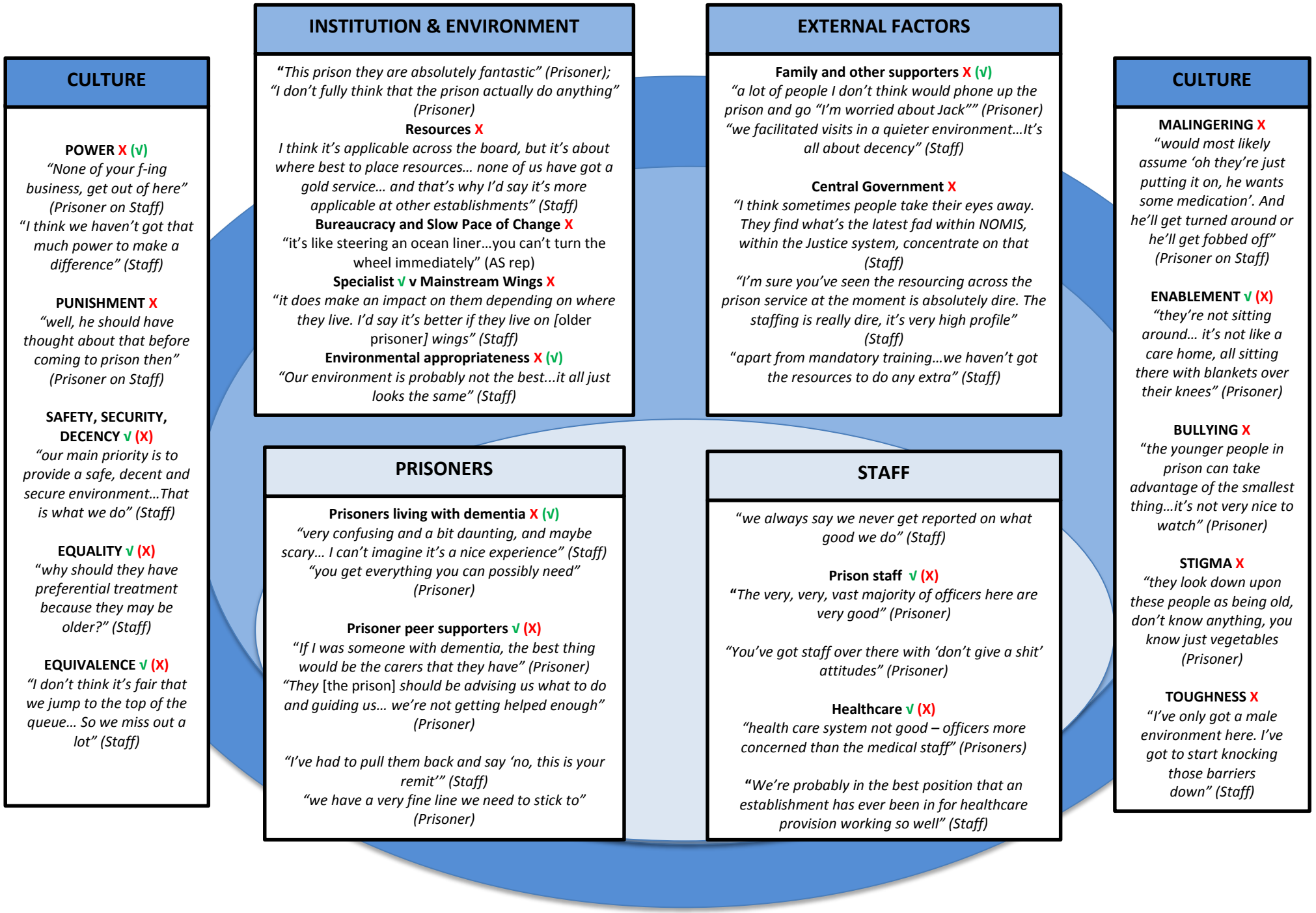

Figure 3: Barriers (x) and Facilitators (√) to applying Dementia Friendly Community principles, and their interactions

Dementia Friendly Prisons

PRE-Dementia Friends Awareness Session Questionnaire

1. **Do you know what Dementia is?** YES NO

   If YES, What is it? ……..

2. **On a scale of 1-10 (1 being a little and 10 being a lot) how much do you know about Dementia?**

   1 2 3 4 5 6 7 8 9 10

3. **What do you know about Dementia? (main things) ……**

4. **Do you know what causes Dementia?** YES NO

   If YES, What? ……

5. **If you wanted to find out more about Dementia while you were in prison where would you look? (Please circle all that apply).**

   Library Internet Television Newspaper Ask Prisoner Rep

   Healthcare Officers Chaplain Friends Family Elsewhere (specify)

6. **Do you think there are any offenders here in HMP …… who may have Dementia?** YES NO

   If YES, do you think there are: a few / a lot / not sure?

   What do you think about Dementia/people with Dementia?……

7. **If you were worried about another offender having Dementia who would you tell? ……**

8. **If you were worried about a family member having Dementia who would you tell? ……**

9. **Can you think of ways you could help an offender with Dementia? Please describe: ……**

10. **On a scale of 1 – 10 (1 being a little 10 being a lot) how confident would you be to talk to others about Dementia?**

    1 2 3 4 5 6 7 8 9 10

11. Do you know what a Dementia Friendly Community is? YES NO

If YES, What is it? ……

12. Would it be useful to learn more about Dementia? YES NO

If YES: WHY would it be useful to learn about Dementia? ……

WHAT would be useful to learn? ……

If NO: Why not? ……

13. Do you think that if staff and offenders learn more about Dementia this will improve the lives of people with dementia in prison? YES NO

If YES, how? ……

If NO, why not? ……

14. Do you think it will improve the lives of everyone else? YES NO

If YES, how? ……

If NO, why not? ……

15. How old are you ……

DEMENTIA FRIENDLY COMMUNITY AIMS QUESTIONNAIRE

Please read the 11 statements below about the experiences of people with Dementia in THIS prison, and indicate how far you agree with each one by ticking the appropriate box. Please also indicate if you believe this has changed over the last year

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Disagree Strongly	HAS THIS CHANGED IN THE LAST YEAR? YES √ For Better	No Change	NO X For Worse
The views of prisoners with Dementia are listened to								
There is a good understanding of Dementia amongst prison staff								
There is a good understanding of Dementia amongst the prisoners								
Prison activities are accessible and appropriate to prisoners with Dementia								
Prisoners with Dementia are made to feel they can make a contribution to prison life								
Early signs of Dementia are picked up on and acted upon, by the staff								
People with Dementia can engage fully in prison life								
Prisoners with Dementia are supported to live as independently as possible								
The prison is easy to get around for people with Dementia								
Prisoners with Dementia are respected								
Prisoners with Dementia face stigma and discrimination here								

SUPPLEMENTARY FILE 3: ADDITIONAL SOCIO-DEMOGRAPHIC DATA FOR STUDY PARTICIPANTS

Table 1: socio-demographic data for the prisoners and staff who participated in the evaluation.

Characteristic	PRISON A (n=38)		PRISON B (n=30)		PRISONERS (n=50)		STAFF (n=18)		TOTAL (n=68)	
	n	%	n	%	n	%	n	%	n	%
Education										
No higher education	7	18.4	14	46.7	14	28	5	27.8	19	27.9
Some higher education +	5	13.2	12	40	12	24	7	38.9	19	27.9
Missing	*26*	*68.4*	*4*	*13.3*	*24*	*48*	*6*	*33.3*	*30*	*44.1*
Marital status										
Single	7	18.4	19	63.3	22	44	4	22.2	26	38.2
Married	5	13.2	7	23.3	4	8	8	44.4	12	17.6
Missing	26	*68.4*	*4*	*13.3*	*24*	*48*	*6*	*33.3*	*30*	*44.1*
Children?										
Yes	8	21.1	18	60	17	34	9	50	26	38.2
No	4	10.5	8	26.7	9	18	3	16.7	12	17.6
Missing	*26*	*68.4*	*4*	*13.3*	*24*	*48*	6	*33.3*	*30*	*44.1*
Race										
White	11	28.9	22	73.3	21	42	12	66.7	33	48.5
Other*	0	0	4	13.3	4	8	0	0	4	5.9
Missing	*27*	*71.1*	*4*	*13.3*	*25*	*50*	*6*	*33.3*	*31*	*45.6*
Religion										
None	2	5.3	8	26.7	5	10	5	27.8	10	14.7
Christian	8	21.1	17	56.7	18	36	7	38.9	25	36.8
Other**	2	5.3	1	3.3	3	6	0	0	3	4.4
Missing	*26*	*68.4*	*4*	*13.3*	*24*	*48*	*6*	*33.3*	*30*	*44.1*
Political Views										
Conservative	2	5.3	4	13.3	5	10	1	5.6	6	8.8
Moderate	6	15.8	14	46.7	16	32	4	22.2	20	29.4
Liberal	2	5.3	2	6.7	2	4	2	11.1	4	5.9
*Missing****	*28*	*73.7*	*10*	*33.3*	*27*	*54*	*11*	*61.1*	*38*	*55.9*

*these were: Afro-Caribbean, African British, Black British, Mixed US/UK
**these were: Buddhist, Muslim

There is a large amount of missing data which impacts all of the socio-demographic variables and categories (prison A/B or staff/prisoner), but has mostly affected Prison A and 'prisoners'. This makes it difficult to interpret the data as it is unclear how representative it is.

BMJ Open

Dementia Friendly Prisons - a mixed methods evaluation of the application of dementia friendly community principles to two prisons in England

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Dementia Friendly Prisons - a mixed methods evaluation of the application of dementia friendly community principles to two prisons in England

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ABSTRACT

Objectives: To apply and evaluate dementia friendly community (DFC) principles in prisons.

Design: A pilot study and process evaluation using mixed methods, with a one-year follow-up evaluation period.

Setting: Two male prisons: a Category C sex offender prison (prison A), and a local prison (prison B).

Participants: 68 participants - 50 prisoners, 18 staff

Intervention: The delivery of dementia information sessions, and the formulation and implementation of dementia friendly prison action plans.

Measures: Study-specific questionnaires; Alzheimer's Society DFC criteria; semi-structured interview and focus group schedules.

Results: Both prisons hosted dementia information sessions which resulted in statistically significant ($p>0.05$) increases in attendees' dementia knowledge, sustained across the follow-up period. Only prison A formulated and implemented a dementia action plan, although a Prison B prisoner dedicated the prisoner magazine to dementia, post-information session. Prison A participants reported some progress on awareness raising, environmental change and support to prisoners with dementia in maintaining independence. The meeting of other dementia friendly aims was less apparent. Numbers of older prisoners, and those diagnosed with dementia appeared to have the greatest impact on engagement with dementia friendly community principles, as did the existence of specialist wings for older prisoners or those with additional care needs. Other barriers and

facilitators included aspects of the prison institution and environment, staff teams, prisoners, prison culture and external factors.

Conclusions: DFC principles appear to be acceptable to prisons with some promising progress and results found. However, a lack of Government funding and strategy to focus action around the escalating numbers of older prisoners and those living with dementia appears to contribute to a context where interventions targeted at this highly vulnerable group can be deprioritised. A more robust evaluation of this intervention on a larger scale over a longer period of time would be useful to assess its utility further.

ARTICLE SUMMARY

Strengths and limitations of this study

- This is the first study published exploring the applicability of dementia friendly community principles in prisons that we have found, and is one of the only studies published worldwide to evaluate the support and/or management of prisoners living with dementia.
- The PPI component of the study was invaluable in establishing the need for dementia-focused work, targeting the intervention and preparing study materials
- Involving people with dementia and their families in the intervention was particularly difficult to achieve in a prison context.
- The relatively small sample size coupled with high prisoner and personnel turnovers made quantitative analysis challenging, and conducting the study in male prisons only is a limitation.
- The number of participants interviewed and involved in focus group discussions provided a rich set of data to explore findings.

KEYWORDS

Dementia, prisoner health, older prisoners, peer support, environment, awareness raising

INTRODUCTION

The number of prisoners over the age of 50[1] in England and Wales has tripled since 2002, and now represents 16.3% of the overall prison population.[1] This is projected to rise further in future.[2-3] Health problems and social care needs are reportedly extensive among this group, estimated to affect over 85% of older prisoners, which has been associated with an approximately three-fold increase in the financial costs of accommodating them compared to the 'general' prisoner population.[4-8] The number of prisoners diagnosed with dementia specifically is unknown, but is at least commensurate with community levels, although likely to be much higher due to the poorer health and lifestyles of prisoners, and the effects of a prison system built for younger, fitter prisoners.[4-5, 9-12] Additionally, people living with dementia in prisons may have harsher prison experiences than their more cognitively able counterparts, which can exacerbate their symptoms, as they are more likely to be vulnerable to victimisation, isolation, and punishment for failing to 'comply' with prison routines.[5, 10, 13-17] It is a matter of national policy that prisons provide a standard of care equivalent to that in the community,[18-19] but a recent parliamentary inquiry has stated that despite some areas of good practice, the government is failing in its duty of care to prisoners in England and Wales.[20]

Dementia has become a health and social care policy priority in the UK, with the Governments' dementia strategy promoting the establishment of Dementia Friendly Communities [DFCs],[21-22] defined as places "where people with dementia are understood, respected and supported".[23, p1] Key DFC principles include: the empowerment and involvement of people with dementia in the formation and

development of communities, increased dementia awareness, challenging stigma, timely access to care, and supportive social and physical environments.[23] Evaluations of DFCs in UK communities mostly reported increases in dementia awareness, but progress on social and environmental change varied and the involvement of people living with dementia were limited in the short-term.[24-30] There have been no published evaluations that we have found applying DFC principles in prisons in England and Wales, nor of any other intervention targeted at people living with dementia in prisons internationally.[31,32] Given the human rights and financial concerns surrounding the imprisonment of people with dementia,[12, 33-35] it seems imperative to explore, implement and evaluate programmes focused on supporting this highly vulnerable population.

RESEARCH AIMS

This study aimed to explore the application of the Alzheimer's Society Dementia Friendly Community principles to two prisons. The research questions were:

1) What progress was made towards applying DFC principles at each prison, following an intervention comprised of information sessions and meetings with the Alzheimer's Society?
2) What was the impact of the intervention?
3) What contextual factors affected implementation of the intervention and DFC principles?

METHOD

STUDY DESIGN

The research was structured as a small-scale pilot study and process evaluation, employing a mixed methods design, with a one-year follow-up period. It was conducted in three stages:

(i) Patient and Public Involvement (PPI)[2] - the involvement of prisoners in the research process was essentially preparatory, establishing the need for dementia-related interventions at each prison, identifiing the people and site for the intervention, and assisting in modifying evaluation materials; actions arising from this involvement were relayed to the prisoners. Prisoners were not directly involved in delivering the intervention, recruiting participants nor conducting the evaluation. Prisoner involvement was not formally evaluated, and so no further findings are reported from this stage of the study.

(ii) Intervention – delivery of hour-long Dementia Friends Alzheimer's Society [AS] information sessions (https://www.dementiafriends.org.uk/WEBRequestInfoSession), and meetings between prison staff and AS to plan and implement DFC-led alterations.

(iii) Evaluation – of the information session, of progress towards implementing DFC principles, and of contextual factors affecting their application, using questionnaires pre- and post-information session and at follow-up, and individual interviews and focus groups at follow-up.

The sequencing of these three stages across the study are shown in Figure 1:

<Figure 1: Study steps>

CONTEXT

This study was conducted in two prisons in the East of England. Prison A was a Category C sex offender prison with 34.2% of the population aged over 50,[36] and two opt-in 120 bed wings for older prisoners (aged >60 years) which had had some adaptation (stair lifts, quiet room). There was also a prison-wide policy for older prisoners to be unlocked through the day. There were reportedly between zero and four prisoners diagnosed with dementia across the course of the study. Prison B was predominantly a local prison[3] with 16.1% of the population over 50,[37] and a 26-bed wing for older prisoners. In addition, there was a 15-bed palliative and significant social care needs wing, with environmental adaptations (normalised dining area, hospital-type beds), which reportedly held five prisoners diagnosed with dementia at follow-up, and ran a cognitive stimulation group. This prison also had 24-hour healthcare staff and an inpatient wing. Both prisons had some prison-wide activities focused on older prisoners (such as dedicated gym/library sessions).

PARTICIPANTS

Forty-six prisoners were involved in the PPI phase of the study (16 from Prison A, and 30 from Prison B). A total of 68 individuals (50 prisoners and 18 staff) participated in the Intervention and Evaluation stages of the study, as detailed in Figure 2:

<Figure 2: Flow of participants>

Forty-five individuals (37 prisoners and 8 staff) attended information sessions, invited by the staff who were leading for the study within each prison, as selected by each prisons' No 1 Governor. Invitations were extended to those likely to be involved in supporting people with

dementia at the prisons and included: older prisoners, prisoner peer supporters and staff working on specialist (older prisoner or health-oriented) wings. Information session attendees were also asked for their consent to be approached to participate in the follow-up evaluation, and were invited to do so by researchers and prison staff leads. Twelve attendees (all prisoners) from prison A participated at 6-months, and a total of seven attendees (6 prisoners and 1 staff member) from both prisons participated at 1-year follow-up. Only two attendees participated at both 6-month and 1-year follow-up, both prisoners.

The remaining 23 follow-up evaluation participants (13 prisoners and 10 staff) who did not attend the information sessions, were comprised of prison staff who led on or participated in the intervention implementation at the prisons (who were invited to take part in the evaluation by the research team), and of additional prisoner peer supporters and prison officers who were interested in dementia at the prisons (who were invited by the prison staff leads). One person with dementia participated in PPI at Prison A, but none were involved in the evaluation, as far as we were aware. The reasons for this are somewhat unclear, as the research team was not directly involved in recruiting prisoners.

MATERIALS

Information sheets and consent forms were developed by the research team and modified according to National Offender Management Service [NOMS] specification. The rest of the materials used were:

(a) Alzheimer's Society Foundation Criteria for the Dementia-Friendly Communities Recognition Process.[38]

(b) Socio-demographic questionnaire (gender, age, education level, marital status, race, children, religion, politics).

(c) Study-specific Information Session Evaluation questionnaire developed by the research team, and modified following prisoner feedback. The questionnaire contained open and closed questions on knowledge, learning and confidence regarding dementia. (see Supplementary File 1)

(d) Study-specific Dementia Friendly Prisons Aims questionnaire, developed by the research team, based on the key DFC principles.[23] (see Supplementary File 2)

(e) The 'Dementia Friendly Physical Environments Checklist'.[39]

(f) Semi-structured interview schedules and focus group frameworks formulated by the research team, focused on the information session, support and barriers for people with dementia, and prison dementia friendliness.

PROCEDURES

As shown in Figure 1, both prisons facilitated PPI activities, and hosted dementia information sessions at which pre- and post-session evaluation questionnaires were collected. Due to sessions over-running, there were difficulties collecting the socio-demographic questionnaire at Prison A. Both prisons' study leads met with AS representatives, but only Prison A created and implemented DFC plans, at which a six-month interim follow-up occurred due to rapidly falling numbers of information session attendees. A full one-year follow-up was conducted at both prisons.

At both follow-up points, evaluation and dementia aims questionnaires were collected, and interviews and focus groups conducted. Across the follow-up evaluation, 11 interviews were conducted with prison staff at suitable locations within and outside of the prison, and six with prisoners during legal visits. All interviews were taped, and one staff interview was scribed by a researcher. A further 24 prisoners participated in focus groups, which were documented on flip chart paper as permission to tape had not been sought in time. In addition, AS representatives (workers identified by AS to work with the prisons for this study) were interviewed, and were invited to do so by the researchers. Prisoners were selected for interview based on the type of peer supporter role they occupied, i.e. those providing direct care assistance to people with dementia (for example, care support orderlies, wheelchair pushers), those providing indirect assistance as a secondary part of their roles (such as library assistants), and prisoner representatives (who represent the views of prisoners at meetings with prison management). The remaining prisoners participated in focus groups.

Informed consent was sought from all participants prior to interviews or focus groups, with researchers going through information sheets and consent forms with potential participants, answering any questions that arose.

DATA ANALYSIS

Quantitative analysis

The data were extracted from the questionnaires by a researcher (ST) who was not involved in the intervention, and entered onto a dataset created using SPSS version 23.[40] One researcher (NDW), who was not involved in either the intervention nor data collection, conducted an independent double-check to identify any incompatible entries. Both researchers (NDW, ST) analysed the data using SPSS. Statistical analysis focused on pre- and post-session and follow-up changes using Chi-squared, McNemar, or Wilcoxan signed-rank tests ($p<0.05$).

Qualitative analysis

All taped interviews were transcribed verbatim which together with focus group flipcharts, were subject to a Framework Analysis.[41] This approach was selected as it could accommodate differing data sources, and provided a clear and systematic structure for a team-based analysis. Using an inductive approach, all researchers: (i) read interviews and noted initial themes; (ii) analysed five transcripts in-depth, noting further themes; (iii) based on this created an analytical framework with main emergent themes; (iv) used this framework to 'code' all material - two researchers independently categorised each transcript using NVivo 11[42] or MS Word[43]; (v) analyses were combined and summarised in an MS Excel[44] spreadsheet, with differences resolved within the team; and (vi) findings were interpreted.

RESULTS

SAMPLE CHARACTERISTICS

A total of 68 individuals (50 prisoners and 18 staff) participated in the Intervention and Evaluation stages of the study. The majority of prisoners identified as male (n=49, 98%), and one prisoner identified as transgender. Conversely, the staff sample was mostly composed of females (n=11, 79%, missing =4). The mean age of the sample was 45.3 years, and ranged from 23-76 years (missing=8). The mean age of the prisoner participants from Prison A (50.6 years) was almost 10 years higher than the prisoner participants of Prison B (40.9 years). This difference was statistically significant (t(44)=2.793, p=0.008). The overall mean age differences between prisons and between prisoners and staff were not statistically significant. With regards to the other socio-demographic variables, there were a large number of missing data making these difficult to interpret, however they have been included as Supplementary File 3.

KEY FINDINGS

This section will discuss the three research questions on progress, impact and context that this study sought to answer, and present an analysis of each.

RESEARCH QUESTION 1: PROGRESS

Both prisons agreed to participate and engaged in the project and evaluation, but they differed in the extent of their engagement. Progress was measured against Alzheimer's Society criteria,[38] which is summarised in Table 1 for each prison.

<Table 1 here>

Table 1: Progress as measured against Alzheimer's Society Foundation Criteria (2014)

CRITERIA	PRISON A	PRISON B
1. Create or join a Dementia Action Alliance (DAA)	(i) Joined the local DAA, attended regularly by prison staff (ii) Prison-only steering group not set up	The prison did not join nor create a DAA or similar
2. Identify a community leader	There was a lead person liaising with the AS rep throughout. This changed several times across the study	The identified lead met with the AS rep once, but a dementia friendly community was not worked towards.
3. Have an awareness raising plan	(i) Information sessions delivered largely to prisoner peer supporters as part of this research; AS rep delivered further session at a prisoner conference (ii) Two staff members trained as dementia champions enabling them to deliver awareness sessions (iii) Information session placed on staff training rotation, delivered by a staff dementia champion (iv) Awareness raising was a part of the prisons' dementia action plan	(i) Information sessions delivered to prisoner peer supporters, and some healthcare and prison staff as part of the research (ii) No known ongoing plan to raise dementia awareness at the prison, and no further information sessions delivered
4. Involvement of people living with dementia, and their carers	(i) Prisoner peer supporters were asked for opinions, but the project was staff-led primarily (ii) Little formal contact between AS rep and prisoners (iii) No known involvement of family or friends of people with dementia	Prison not working towards establishing a dementia friendly community within this project, so no prisoner nor family or friends involved.
5. Publicise the work of the community	(i) The dementia action plan was posted on the DAA website (ii) The AS rep was a speaker at a prison-wide conference for prisoner peer supporters (iii) Staff working outside of specialist wings appeared unaware of the project	(i) There was no dementia friendly community plan (ii) A prisoner who attended the information session as part of this research, used the information to create an edition of the in-house prisoner magazine focused on dementia
6. Focus the action plans on two or three key priorities	A dementia action plan was created focused on: raising awareness; improving the physical environment; and working with partners inside and outside the prison	No dementia action plan was created
7. Have a 6-month and annual evaluation plan	(i) The prison participated in the research evaluation. The prison was continuing to work with AS and DAA, but unclear about ongoing plans to evaluate	The prison participated in the research evaluation – no further evaluation plans made

Prison A met a number of the criteria which included joining a local Dementia Action Alliance[4], creating a DFC plan which was posted on the internet, running awareness raising events, and making small environmental changes – such as having planters in a specialist wing yard. Actions in these areas were reportedly ongoing although slow, and mostly implemented within the older prisoner wings:

> *"I feel I've been so lucky to be involved in this project…it's one of the few places that I've been where they've actually listened... and it's slow, but it's going to be slow, you just have to accept that. But, they do listen, and every time I go …something has happened in relation to what I've talked about previously. And that is so unique" (Prison project worker).*

Whilst Prison B engaged with the intervention initially (hosting information sessions and meeting with an AS representative), there was little progress beyond this, with few AS criteria met and no DFC plans created. The lack of continued engagement largely centred around there being lower numbers of older prisoners at this prison, with other issues prioritised as a result, and the belief that services for people with dementia at the prison were good enough already. A prisoner at Prison B did use the information session materials to produce an edition of the prison magazine focused on dementia, and the difficulty of being in prison when family are experiencing dementia or supporting others with dementia.

RESEARCH QUESTION 2: IMPACT

Within this study, impact was assessed using study specific questionnaires evaluating (i) the dementia information session, and (ii) whether DFC aims were met, and if changes were made by the prison to support these. As no DFC plans were made or implemented at Prison B, analysis of questionnaire (ii) will only be presented for Prison A. Quantitative results will also be augmented by interview and focus group analyses.

(a) Information session evaluation

Participants completed questionnaires evaluating the information session pre- (n=45) and post-session (n=40), and at six-months (n=12) and one-year follow-up (n=7). This was also explored further in interviews and focus groups. Table 2 shows data taken from the questionnaires across the evaluation period:

<Table 2 here>

All of the responses concerning perceived knowledge of dementia increased post-session, reaching statistical significance for level of knowledge about dementia, its causes and dementia friendly communities. Participants also reported feeling more confident talking to people with dementia post-awareness session. At 6-months and one-year follow-up, participants continued to report that they knew more about dementia than they had pre-awareness session, differences which were statistically significant. Unsurprisingly, no results were significant for the three participants sampled at both 6-months and 1-year follow-up.

Some participants also reported that the session altered the way they supported people living with dementia in the prison, with a positive knock-on effect on those relationships.

Table 2: Descriptive statistics and comparative analyses of awareness session questionnaires

	PRE-COMPARISON ANALYSIS			POST-COMPARISON ANALYSIS		FOLLOW-UP ANALYSIS
	Pre-Post (n=38)	**Pre - 6-mth (n=12)**	**Pre - 1-year (n=7)**	**Post - 6 mth (n=11)**	**Post - 1-year (n=5)**	**6-mth – 1 year (n=3)**
Do you know what dementia is? *(N° Yes, %; significance level)**	31(86.1)-36(100) p=0.063 *2 missing*	n/a	n/a	n/a	n/a	n/a
How much do you know about dementia? *(median; significance/level)***	4 - 7 Z=-4.594, p<0.001 *1 missing*	5 - 6 Z=-2.831, p= 0.005	5 - 6 Z=-2.232, p=0.026	7 - 6 Z=-1.311, p=0.190	7 – 4 Z=0, p=1.000 *1 missing*	6 -4 Z=-1.414, p=0.157
Do you know the causes of dementia? *(N° Yes, %; Significance level)**	7(25) – 24(85.7) p<0.001 *10 missing*	n/a	n/a	n/a	n/a	n/a
Do you know what a dementia friendly community is? *(N° Yes, %; Significance level)**	13(44.8)-26(89.7) p<0.001 *9 missing*	7(70.0) - 9(90.0) p=0.500 *2 missing*	1(16.7) – 5 (83.3) p=0.125 *1 missing*	9(90.0) – 8(80.0) p=1.000 *1 missing*	3(100) – 3(100) p=1.000 *2 missing*	3(100)– 3(100) p=1.000
Did the awareness session increase your knowledge/did you learn? *(No, %; Significance level)**	n/a	n/a	n/a	10 (100)– 9 (90.0) p=1.000 *1 missing*	4 – 4 (100) p=1.000 *1 missing*	3(100) – 3 (100) p=1.000
Confidence in talking about dementia to others? *(median; significance/level)***	5 – 7 Z=-3.917, p<0.001 *8 missing*	5 - 7 Z=-0.854, p=0.393	5 – 6 Z=-1.069, p=0.285 *3 missing*	7 - 7 Z=-1.897, p=0.058	7 - 6 Z=0, p=1.000 *1 missing*	7 - 6 Z=0, p=1.000
Confidence in helping people living with dementia? *(median; significance/level)***	n/a	n/a	n/a	n/a	n/a	8 – 7 Z=0, p=1.000
Did the awareness session change your views on people with dementia? *(N° Yes, %; Significance level)**	n/a	n/a	n/a	n/a	n/a	3 – 3 (100) p=1.000

*Significance testing using exact McNemar's test
**Significant testing using Wilcoxon signed-rank test

= statistically significant

There were also reports of participants finding the information personally comforting and useful in supporting colleagues, and also extending to their communities of friends and family outside of prison:

> *"For me it helped me mostly because my grandad suffers with dementia… for me* [the information session] *put my mind at ease a lot with that and helped me. And I talked with my mum and my grandma about it a lot more because of that, because I felt a bit more confident having that knowledge" (Prisoner)*

(a) *Dementia Friendly Prison Aims*

Table 3 shows study participants' views on whether Prison A met DFC aims at 6 months (n=15) and 1-year follow-up (n=12), using the DFC aims questionnaire. These were largely independent samples, therefore a comparative analysis was not possible.

<Table 3: Dementia Friendly Prison Aims questionnaire table>

At both six-months and one-year follow-up, the majority of participants reported that people with dementia in the prison did not face stigma and discrimination and were supported to live independently at the prison. At 6-months, the latter was reported to have improved – the only area in which participants reported positive change across the study. It is possible that this reflects that prisons in general expect prisoners to function independently within parameters, but in addition, Prison A had adopted a policy of 'enablement', which appears to be compatible with this DFC aim:

Table 3: Dementia Friendly Prison Aims and Changes made to Prison A

DEMENTIA FRIENDLY PRISON AIMS	SIX-MONTH FOLLOW-UP (n-15)								ONE-YEAR FOLLOW-UP (n=12)							
	Aims met?		Change over last 6 months						Aims met?		Change over the last 6 months					
			For better		*No change*		*For worse*				*For better*		*No change*		*For worse*	
	n	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Views of people with dementia are listened to	**5**	**33.3**	4	26.7	6	40	3	20	**3**	**25**	3	25	6	50	0	0
Good understanding of dementia amongst prison staff	**2**	**13.3**	2	13.3	10	66.7	2	13.3	**2**	**16.7**	2	16.7	4	33.3	2	16.7
Good understanding of dementia amongst prisoners	**5**	**33.3**	5	33.3	8	53.3	1	6.7	**2**	**16.7**	3	25	4	33.3	1	8.3
Accessible and appropriate prison activities for people with dementia	**4**	**26.7**	1	6.7	11	73.3	2	13.3	**3**	**25**	0	0	7	58.3	1	8.3
People with dementia are made to feel they can contribute to prison life	**4**	**26.7**	3	20	8	53.3	3	20	**3**	**25**	0	0	7	58.3	1	8.3
Staff pick up and act upon early signs of dementia	**2**	**13.3**	4	26.7	8	53.3	1	6.7	**2**	**16.7**	1	8.3	6	50	1	8.3
People with dementia can engage fully in prison life	**6**	**40.0**	4	26.7	8	53.3	1	6.7	**4**	**33.3**	1	8.3	7	58.3	0	0
People with dementia are supported to live as independently as possible	**10**	**66.7**	**6**	**40**	**4**	**26.7**	**3**	**20**	**10**	**83.3**	**3**	**25**	**6**	**50**	**0**	**0**
The prison is easy to get around for people with dementia	**4**	**26.7**	1	6.7	8	53.3	3	20.0	**4**	**33.3**	0	0	7	58.3	1	8.3
People with dementia are respected	**4**	**26.7**	1	6.7	9	60	4	26.7	**5**	**41.7**	1	8.3	6	50	1	8.3
People with dementia face stigma and discrimination here	**4**	**26.7**	3	20.0	8	53.3	2	13.3	**4**	**33.3**	1	8.3	6	50	1	8.3

"I'm forever saying 'enable', enable as much as possible. Encourage them to clean, encourage them to tidy their cell up… get them doing as much as possible. [Person with dementia*], for all the will in the world you couldn't take work away from him, he just wants to do it himself…we're never going to take that off him" (Prisoner)*

Regarding the other DFC aims, only around a third or less of participants agreed that they had been met. This included two foci of Prison A's DFC action plan: ease of navigation and understanding and identifying symptoms of dementia, particularly amongst staff. Whilst on the one hand this may represent a lack of observable progress in these areas, it may also reflect that the dementia-focused work at Prison A was largely implemented across two older prisoner wings rather than prison-wide. This was indicated by staff participants who worked on mainstream wings reporting that they were unaware of the DFC project, and also by prisoner observation:

"I think those that work specifically on [older prisoner wings], *I think they're becoming more aware. But as the others, they got a very mixed bag. A very mixed bag" (Prisoner)*

RESEARCH QUESTION 3: CONTEXTUAL FACTORS

An analysis of staff and prisoner interviews and focus group discussion identified elements of the prison context which could act as barriers or facilitators to the implementation of DFC

principles. These were related to: (i) institution and environment, (ii) staff, (iii) prisoners, (iv) prison culture and (v) external factors. These are depicted in Figure 3 with apposite quotations, and are discussed further below.

<Figure 3: Barrier and Facilitators>

(i) Institution and Environment

Prison budget cuts and bureaucracy were reported to impact engagement with the intervention, and implementation. Staff reported that the larger number of older prisoners and relative stability of the prisoner population at prison A justified greater engagement with the project (although this fluctuated according to numbers of prisoners with a dementia diagnosis). At prison B, staff reported that the lower numbers of older prisoners and the amount of prisoner turnover could not justify continued engagement – mental health problems and substance misuse were clearer priorities. Staff leads at this prison also reported that they felt their support of people with dementia was good enough already.

Overall, staff and prisoner opinion of the dementia friendliness of both of the prisons was mixed. Specialist wings were largely considered more suitable for people with dementia than mainstream wings, as they were considered to be safer and less isolating, with more relaxed regimes and activities. Opportunities to socialise outside of the specialist wings at Prison A was considered positively, although some felt activities were too few at both prisons. Environmentally, the specialist wings were reportedly easier to navigate and more comfortable than mainstream wings. However, it was widely agreed that these fell short of dementia friendliness (for example, cell doors not wide enough for wheelchairs at prison A,

and lack of stair lifts at prison B), as did the prisons overall, which were reportedly difficult to get around. Relaxed regimes, activities and adaptations were all affected by budget cuts.

(ii) Staff

There were mixed reports from prisoners and staff on prison- and healthcare staff support for people with dementia in the prisons. Prison staff regularly working on specialist wings were described as more dementia aware and supportive of people with dementia, than staff working on mainstream wings. However, this more supportive practice seemed dependent on whether staff were able to choose this work. The introduction of social care at prison A and the presence of 24-hour healthcare staff at prison B were considered a potential benefit to people with dementia. There were mostly positive reports of most healthcare staff at both prisons, but there was some concern expressed about the more 'security' focused operation of the inpatient wing and staff at prison B. Some participants also suggested that healthcare staff seemed reluctant to make dementia diagnoses – with reports of prisoners with dementia symptoms outstripping numbers diagnosed, affecting treatment and also prison decisions to engage with dementia-related interventions.

(iii) *Prisoners*

Reports of the experiences of people with dementia at both prisons varied, but most participants suggested that it was likely to be confusing or frightening. Peer supporters providing direct care support for those with dementia were considered to provide vital support at Prison A – possibly as a result of less healthcare cover. The number of peer supporters at both prisons were seen as too few by most participants, with training, support and guidance around dementia mostly reported as inadequate, and a lack of formal

contracts making roles unclear at prison A. It is of note that healthcare staff were reported to offer peer supporters good informal support on one of the specialist wings at prison B.

(iv) Prison Culture

There were a number of aspects of prison policy, practice and culture which appeared to be compatible with DFC principles: *safety, security and decency* as guiding operating goals*; equality* in the application of rules; *equivalence* of care between prisons and the community; and at Prison A e*nablement*. However, it seemed that some of these were applied patchily or too rigidly at times to be supportive, such as an expectation that all prisoners conform to rules *equally* irrespective of cognitive capacity, or a lack of *decency* in not offering through-the-night incontinence care.

Other aspects of prison culture were identified that could affect the support of people with dementia, as well as the likelihood of prisoners seeking help. These included: how the *punishment* of prison was perceived - prison as punishment or prison for punishment; perceptions of prisoners as potentially *malingering* or *manipulative; a* somewhat *'macho'* culture*; bullying and exploitation* (although only a couple of instances were reported)*;* and *stigma* about age – which seemed to have some effect on prisoners' choice of accommodation and staff desire to work with this group. It is also of note that *power* relationships suffuse prison culture. Some manifestations of this reported were: fear of censure resulting in the reluctance of some peer supporters to advocate for people with dementia in the prison, and for more junior prison staff to challenge practice.

(v) *External Factors – family/friends and central government*

There were a couple of examples of liaison between prison staff and family (mostly when prisoners were dying or had died), family visits facilitated in quiet spaces, and the involvement of a charity that facilitated family connections at both prisons. However, there appeared to be a lack of mechanisms/policy in place to maintain links between family/friends and people with dementia in both prisons, which included assistance with telephone calls, and for family to report concerns or receive support, and some reports of other prisoners risking punishment to assist.

Central governments' austerity-driven cuts were reported to impact the whole prison system in myriad ways. The lack of policy and strategy attention for people living with dementia appeared to amplify the effect. Given both prisons reportedly struggled with implementing mandatory operations and training, attending to issues that are not mandatory seemed to render the status of additional dementia input as a "luxury" (Staff).

DISCUSSION

Summary of results

Both of the participating prisons reported that DFC principles were applicable to them, but differed in the extent to which they engaged with the intervention. Dementia information sessions were delivered at both, and reportedly increased participants' knowledge, confidence, and understanding of dementia, consistent with community DFC evaluations.[24-30] Prison A created and implemented a DFC action plan, facilitated additional awareness raising initiatives, small environmental changes, and reportedly helped people with dementia to live more independently – but, progress was considered slow and was mostly focused on older prisoner wings. Prison B did not create nor implement a DFC

action plan. Facilitators and barriers for the implementation of DFC principles largely flowed from where individuals living with dementia chose to reside, with older prisoner-focused wings considered more dementia friendly, with more 'aware' staff and peer supporters. Austerity-related cuts to prison budgets presented one of the biggest barriers to implementation and to decisions to engage in the intervention – which was also driven by numbers of older prisoners and people with dementia diagnoses.

Study strengths and limitations

Study strengths and limitations divide into those related to the fidelity of the intervention at Prison A, and those related to the running of the evaluation at both prisons.

Intervention

Although most AS intervention criteria were met, one of the key DFC principles proved challenging: involving people with dementia (although this was also a difficulty for community interventions).[24-30] Within this study, this appeared to be partly due to fluctuating numbers of prisoners formally diagnosed with dementia, which also affected the evaluation. Additionally, DFC plans were largely created by the prison lead alone, but a steering group including people with dementia in the prison, family, peer supporters, and staff from across the prison, could establish and maintain a prison DFC more consistent with AS's central tenets. The AS did not 'train' prisoners as Dementia Champions as part of this project. Overcoming bureaucratic obstacles to doing so would also be more consistent with DFC principles.

Evaluation

This is the first published evaluation of the Government-endorsed DFC approach to prisons, and – as a small-scale study – was essentially exploratory, taking place in only two prisons, and with no control groups. The PPI phase of the study proved valuable in targeting the work and ensuring materials were workable, although an expanded role for prisoner involvement in design, recruitment and execution would have been desirable. The sample size for the information session evaluation was relatively small, and significantly reduced across the follow-up period affecting sub-group analyses, as did the lack of socio-demographic data. A 'traditional' one-year follow-up study of a prison-based intervention may be impossible on a small-scale due to high prisoner and staff turnover – larger sample sizes, or briefer follow-up periods may be more feasible.

Implications and recommendations

The biggest challenge to the implementation of DFC principles in both prisons seemed to come from the significantly reduced budgets allocated since 2010, resulting in a quarter of the prison workforce being cut,[45-46] and contributing to record levels of prisoner violence and self-harm.[47-50] As older prisoners typically pose less problems and reoffend less than their younger counterparts,[51-54] their difficulties are in danger of going unrecognised, underscored by the Government's repeated refusal to create a strategy focused on them.[16, 55-60] Centralised resources and strategy are fundamental in the early release of people living with dementia in prison, which is currently rarely used, in guiding and funding better health and social care, and more appropriate social and physical environments. However, from the evaluation there were a number of more locally-controlled practices identified that could facilitate DFC practice, some of which could be co-designed and delivered with external organisations:

- Partial segregation of older prisoners on wings that are 'opt-in' for both prisoners and staff, with trained and supported staff and peer supporters,[59] a comprehensive programme of activities, and opportunities for prisoners to leave the wing to access prison-wide activities and services if desired.[61-62]
- Dementia information sessions made available to the wider prison, to include a reflection of the impact of prison and its culture on people with dementia, and examples of good prison dementia practice from specialist wings or health/social care.
- Policies for older prisoners and those with dementia which allow them to be unlocked, to receive retirement pay commensurate with working peers' pay, and to access appropriate activities – potentially at an off-wing centre.
- Use of in-house expertise, labour, and adaption of simple DFC design to improve environments.[63-65]
- Access to specialist dementia training for healthcare staff where needed, and a clear referral pathway to specialist dementia services in the community. Dementia awareness could be included as part of broader health promotion activities.
- Review and translate local policies, practices and procedures for older prisoners and people with dementia, including disciplinary and restraint procedures. Resultant training can address more problematic aspects of prison culture, including stigma, bullying, and malingering assumptions – linked as they are to prison suicide.[66]
- To systematically support the links between people living with dementia in prison and their family to be more in line with NICE guidelines[67]. For example, to assist telephone calls, facilitate travel to visits in quiet spaces, increase liaison between

family/friends and the prison, and support family and friends in coping with the distress of having a loved one in prison with dementia.

Future research

This was a pilot study that produced some promising findings warranting further investigation, such as a more robust evaluation with a larger sample size, across a variety of prisons, for longer periods. Exploring the intersectionality of other protected characteristics (for example gender and ethnicity) with age and dementia, will be particularly important to ensure the community is applicable to all.

The role of prisoner peer supporters for people with dementia in prison appeared to be key in this study, and as to date there have been no published evaluations of their work, additional study would be valuable.[68] There is a particular lack of research focused on people living with dementia in prisons and upon the challenges of resettlement[69], so further research on their experiences and the most effective ways to support them, would likely be useful to prison practitioners, researchers and policy makers.

CONCLUSION

In the two prisons involved in this pilot study and process evaluation, DFC principles were considered applicable, and information sessions reportedly positive, but only one prison continued to work with the Alzheimer's Society in creating and implementing DFC plans. A number of contextual factors appeared to impact both engagement with the study and also in dementia friendly practice in prisons in general. However, perhaps the most fundamental was the balancing of resources - having to make difficult decisions about whether the

numbers of both older prisoners, and prisoners with dementia, were sufficiently high to justify engagement with non-compulsory dementia-focused interventions in a context of Government-sanctioned austerity and budget cuts. Without policy at Government-level to focus attention on one of the most vulnerable groups living in prison, it may only be prisons with very large numbers of older prisoners that can justify interventions targeting prisoners with dementia, which raises moral, legal and ethical concerns for those who do not.

FOOTNOTES

[1] *The age cut-off for 'older prisoner' varies, but is typically thought to be 10 years younger than the general population, as prisoners have been reported to age more rapidly due to lifestyle, healthcare access, substance misuse, and the stress of imprisonment (see [70] for further discussion)*

[2] "*Patient and Public Involvement has been described as "research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them" [71]. So, prisoner involvement in the research process itself, as distinct from being a 'participant' in research interventions or evaluations.*

[3] *Local prisons serve the courts local to the prison, holding prisoners on remand, those serving shorter sentences and those serving longer sentences awaiting allocation to another prison.*

[4] *Organisations join local Dementia Action Alliances to "share best practice and take action on dementia" [72]*

[5]*anonymised to preserve confidentiality*

AUTHOR CONTRIBUTIONS

Samantha Treacy – design of study materials; facilitated focus groups and conducted interviews; led qualitative analysis, and conducted quantitative analyses; drafted the manuscript as lead author.

Anna Haggith – involvement with project conception and design; liaison with project partners; co-designed study materials; facilitated PPI/E, awareness sessions, interviews and focus groups; conducted qualitative analysis; contributed comments to manuscript drafts.

Nuwan Darshana Wickramasinghe – conducted quantitative analysis and qualitative analyses; edits to manuscript drafts.

Tine Van Bortel – Principle Investigator: conceived of and designed the study and grant proposal; oversaw and advised on all aspects of the study; design of study materials; liaison with project partners; contributed comments and edits to manuscript drafts.

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DISCLAIMER

The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care, nor of Her Majesty's Prison and Probation Service.

COMPETING INTERESTS

None declared.

PATIENT CONSENT

Not required.

ETHICS APPROVAL

Advice was sought from the Anglia Ruskin University ethics committee, and full ethical approval for the study was granted by the National Offender Management Service (NOMS) – National Research Committee, with further permission obtained from the Governors of each participating prison.

PROVENANCE AND PEER REVIEW

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DATA SHARING STATEMENT

Deidentified participant data are available from Orcid ID 0000-0003-0467-6393 upon request

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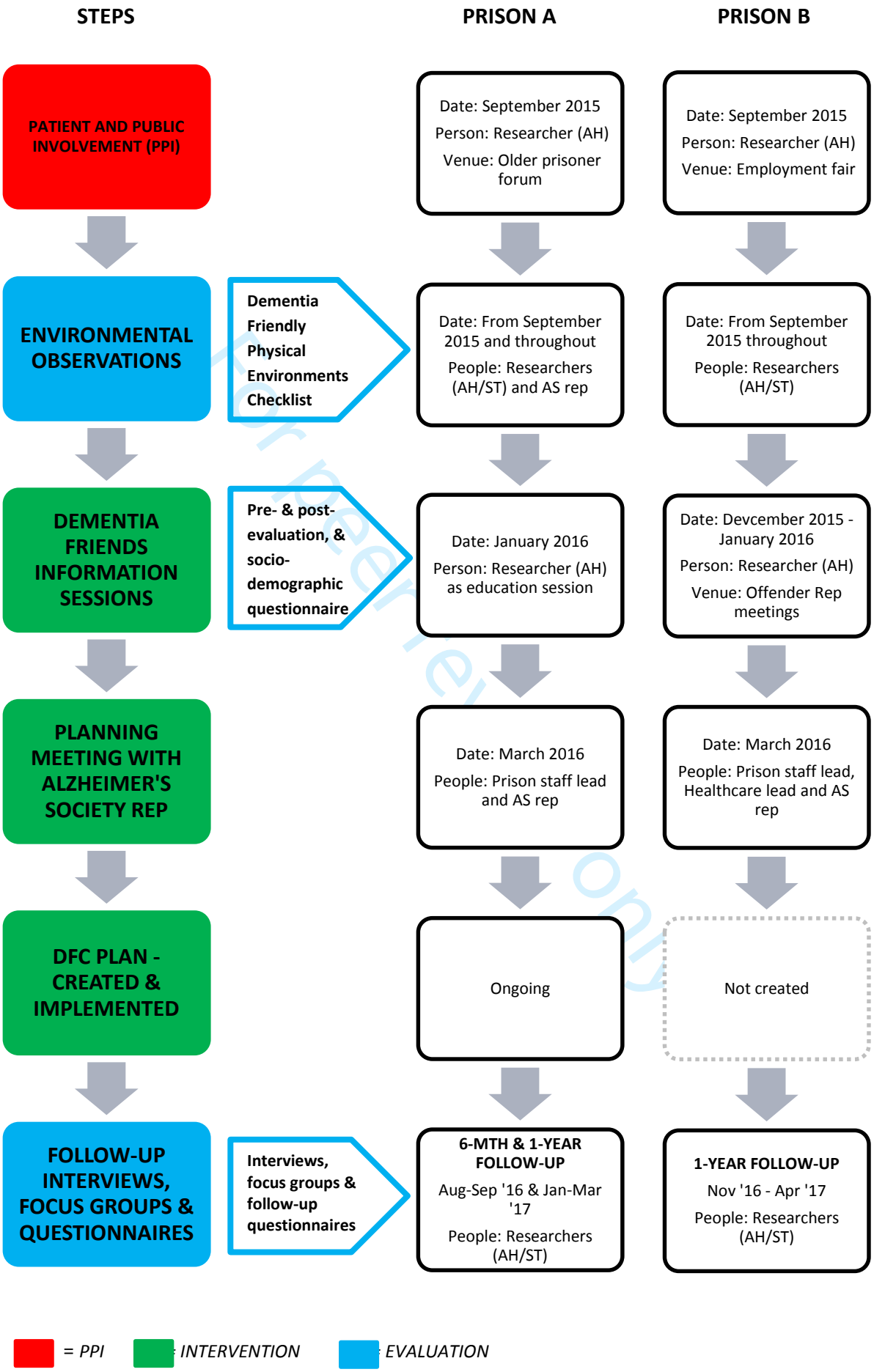

Figure 1: Steps involved in the study

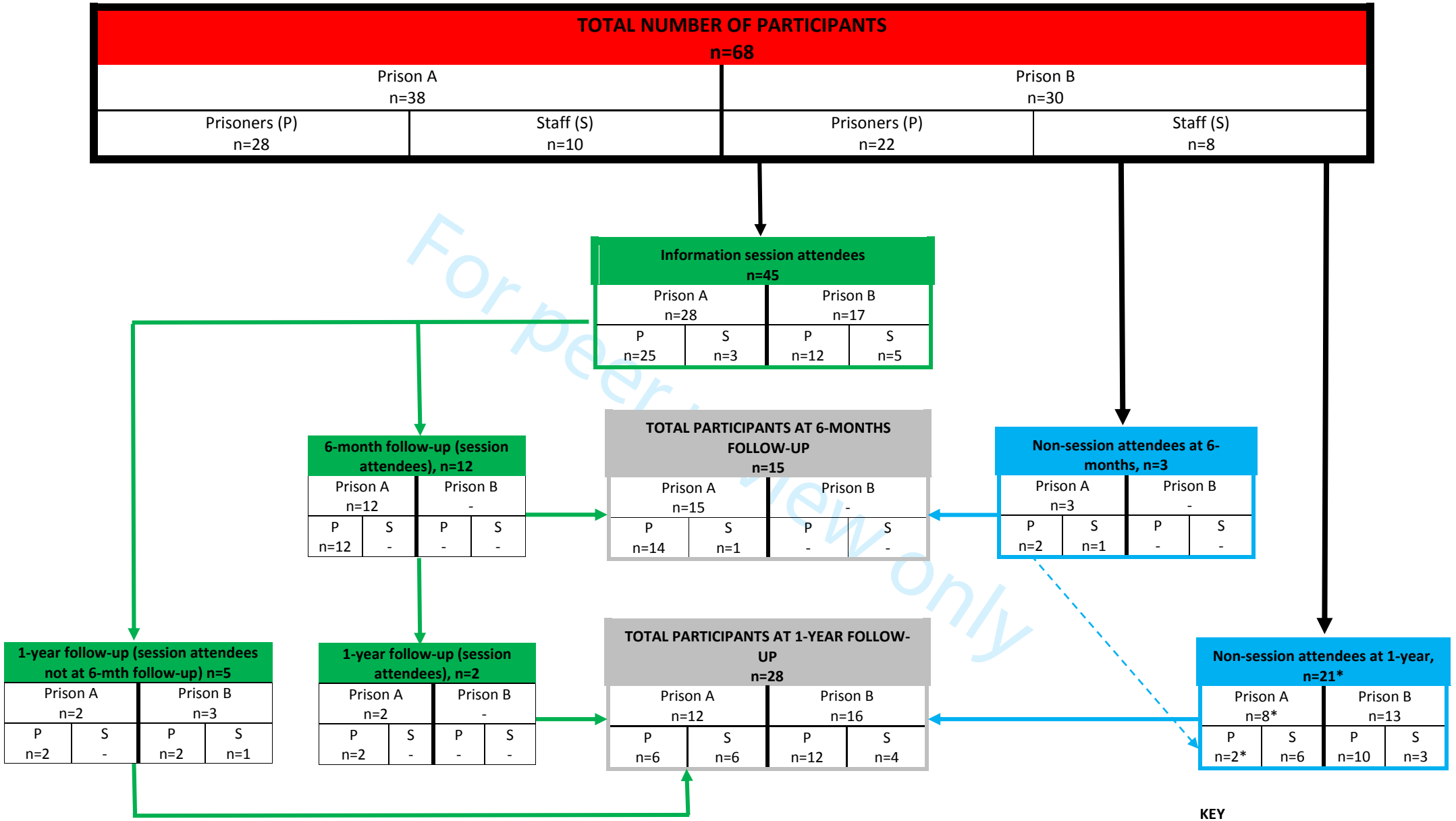

Figure 2: Flow of participants through the Intervention and Evaluation stages of the study

* One prisoner from Prison A did not attend the information session, but was involved at both 6-month and 1-year follow-up

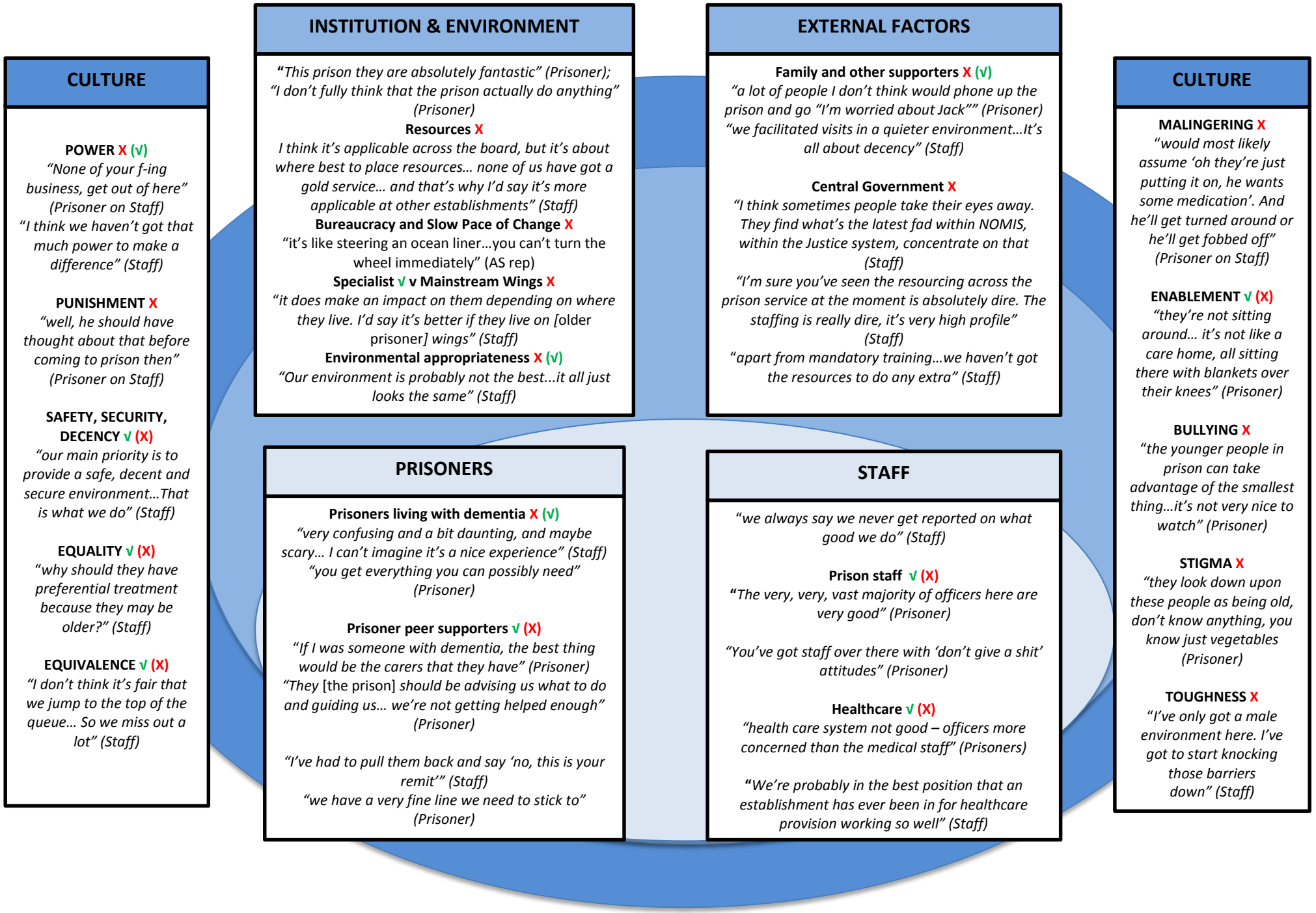

Figure 3: Barriers (x) and Facilitators (√) to applying Dementia Friendly Community principles, and their interactions

Dementia Friendly Prisons

PRE-Dementia Friends Awareness Session Questionnaire

1. **Do you know what Dementia is?** YES NO

   If YES, What is it? ……..

2. **On a scale of 1-10 (1 being a little and 10 being a lot) how much do you know about Dementia?**

   1 2 3 4 5 6 7 8 9 10

3. **What do you know about Dementia? (main things) ……**

4. **Do you know what causes Dementia?** YES NO

   If YES, What? ……

5. **If you wanted to find out more about Dementia while you were in prison where would you look? (Please circle all that apply).**

   Library Internet Television Newspaper Ask Prisoner Rep

   Healthcare Officers Chaplain Friends Family Elsewhere (specify)

6. **Do you think there are any offenders here in HMP …… who may have Dementia?** YES NO

   If YES, do you think there are: a few / a lot / not sure?

   What do you think about Dementia/people with Dementia?……

7. **If you were worried about another offender having Dementia who would you tell? ……**

8. **If you were worried about a family member having Dementia who would you tell? ……**

9. **Can you think of ways you could help an offender with Dementia? Please describe: ……**

10. **On a scale of 1 – 10 (1 being a little 10 being a lot) how confident would you be to talk to others about Dementia?**

    1 2 3 4 5 6 7 8 9 10

11. Do you know what a Dementia Friendly Community is? YES NO

If YES, What is it? ……

12. Would it be useful to learn more about Dementia? YES NO

If YES: WHY would it be useful to learn about Dementia? ……

WHAT would be useful to learn? ……

If NO: Why not? ……

13. Do you think that if staff and offenders learn more about Dementia this will improve the lives of people with dementia in prison? YES NO

If YES, how? ……

If NO, why not? ……

14. Do you think it will improve the lives of everyone else? YES NO

If YES, how? ……

If NO, why not? ……

15. How old are you ……

DEMENTIA FRIENDLY COMMUNITY AIMS QUESTIONNAIRE

Please read the 11 statements below about the experiences of people with Dementia in THIS prison, and indicate how far you agree with each one by ticking the appropriate box. Please also indicate if you believe this has changed over the last year

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Disagree Strongly	HAS THIS CHANGED IN THE LAST YEAR? YES √ For Better	No Change	NO X For Worse
The views of prisoners with Dementia are listened to								
There is a good understanding of Dementia amongst prison staff								
There is a good understanding of Dementia amongst the prisoners								
Prison activities are accessible and appropriate to prisoners with Dementia								
Prisoners with Dementia are made to feel they can make a contribution to prison life								
Early signs of Dementia are picked up on and acted upon, by the staff								
People with Dementia can engage fully in prison life								
Prisoners with Dementia are supported to live as independently as possible								
The prison is easy to get around for people with Dementia								
Prisoners with Dementia are respected								
Prisoners with Dementia face stigma and discrimination here								

SUPPLEMENTARY FILE 3: ADDITIONAL SOCIO-DEMOGRAPHIC DATA FOR STUDY PARTICIPANTS

Table 1: socio-demographic data for the prisoners and staff who participated in the evaluation.

Characteristic	PRISON A (n=38)		PRISON B (n=30)		PRISONERS (n=50)		STAFF (n=18)		TOTAL (n=68)	
	n	%	n	%	n	%	n	%	n	%
Education										
No higher education	7	18.4	14	46.7	14	28	5	27.8	19	27.9
Some higher education +	5	13.2	12	40	12	24	7	38.9	19	27.9
Missing	*26*	*68.4*	*4*	*13.3*	*24*	*48*	*6*	*33.3*	*30*	*44.1*
Marital status										
Single	7	18.4	19	63.3	22	44	4	22.2	26	38.2
Married	5	13.2	7	23.3	4	8	8	44.4	12	17.6
Missing	26	*68.4*	*4*	*13.3*	*24*	*48*	*6*	*33.3*	*30*	*44.1*
Children?										
Yes	8	21.1	18	60	17	34	9	50	26	38.2
No	4	10.5	8	26.7	9	18	3	16.7	12	17.6
Missing	*26*	*68.4*	*4*	*13.3*	*24*	*48*	6	*33.3*	*30*	*44.1*
Race										
White	11	28.9	22	73.3	21	42	12	66.7	33	48.5
Other*	0	0	4	13.3	4	8	0	0	4	5.9
Missing	*27*	*71.1*	*4*	*13.3*	*25*	*50*	*6*	*33.3*	*31*	*45.6*
Religion										
None	2	5.3	8	26.7	5	10	5	27.8	10	14.7
Christian	8	21.1	17	56.7	18	36	7	38.9	25	36.8
Other**	2	5.3	1	3.3	3	6	0	0	3	4.4
Missing	*26*	*68.4*	*4*	*13.3*	*24*	*48*	*6*	*33.3*	*30*	*44.1*
Political Views										
Conservative	2	5.3	4	13.3	5	10	1	5.6	6	8.8
Moderate	6	15.8	14	46.7	16	32	4	22.2	20	29.4
Liberal	2	5.3	2	6.7	2	4	2	11.1	4	5.9
*Missing****	*28*	*73.7*	*10*	*33.3*	*27*	*54*	*11*	*61.1*	*38*	*55.9*

*these were: Afro-Caribbean, African British, Black British, Mixed US/UK

**these were: Buddhist, Muslim

There is a large amount of missing data which impacts all of the socio-demographic variables and categories (prison A/B or staff/prisoner), but has mostly affected Prison A and 'prisoners'. This makes it difficult to interpret the data as it is unclear how representative it is.