BANES Carers' Centre Report to Healthwatch BANES Report Appendix

Session write ups covering sessions in February, March, September, October, November, December 2019

Carers' Centre
Bath and North East Somerset

healthwatch
Bath and North East Somerset

Learn to lead

Carers’ Voice Group Thursday 28th February 2019 Session Write Up

The communities that the individual carer belongs to

Thinking in terms of the place of the individual carer within their wider community, this exercise maps out the various communities of belonging that the carer is placed within. This exercise provides context for the project as it is intended to be community-led.

Individual Carer
↓
Condition-specific support groups (such as Faces, Dementia Café’s, KS2, ADHD Support groups, Carers for Each Other – Carers’ Centre supported Groups)
↓
BANES Carers Centre – Non-specific support services
↓
Wider carer community
↓
Wider non-carer community (including businesses)
↓
Local authorities / decision makers (such as Virgin Care, CCG)
↓
Regional Authority
↓
National Government
↓
National population (voters, citizens)
↓
Media (public awareness)

Why are you here? What do you want to do?

To be able to have input and influence local services that are important to my daughter and the rest of the family; To meet others in a similar situation hoping to pick up useful info; To not be isolated as a carer; To use any skills I have after giving up work.

I want to be proactive with services that are important to me and my family; To improve lives for all in a similar situation; Keep promoting what is needed for young adults who are often left out over age 25.

To meet other carers and spend time with people who ‘get me / my life’.
I want to make people better understand the lives of carers; To improve things for carers, and their lives; To increase the numbers of carers who are aware of, and access, the Carers Centre; To be listened to.

I am here because I volunteered to speak up for carers and the Carers Centre.
I want to have a voice and change things for carers and the cared for person; I want the change to be ‘considered’ and involve as many carers as possible; I want the influence to improve services for carers, not a quick fix but well thought out and solid for future carers; More understanding of carers’ needs from the general public; Shops/organisations to be trained to assist/welcome carers.

To raise awareness of caring communities; To support other carers.
I want to give back to Carers Centre as an ambassador.

I am here to listen and learn from the group and to take away ideas.
I want to act on the ideas from the group meetings when I can.

I am here because I am very passionate about ensuring carers have a voice. As a carer myself I can also give from a carer perspective as well as from a professional point of view.
I want to ensure carers can get involved and have a voice in ways that suit them, and in matters/issues that are important to them. I want to ensure their voices are heard, respected and valued by decision makers, making an impact on the lives of all carers.

I’m here because the experience of carers matters to me. It is and has been a big part of my life. Working with the Carers Centre is an opportunity to do more to support these people and this community I care about.
I want to support carers and their surrounding communities to take more of an active role in influencing the services that affect them. In a way that is inclusive, open and sustainable.

Comments

The experience of being a carer can be difficult, sometime accompanied with feelings of guilt or being overwhelmed. The Carers Centre provides a service that addresses this, and reduces isolation which is crucial. But many people who may or may not even think of themselves as carers aren’t aware of the centre and what it can provide for them.

Carers' Voice Group Thursday 21st March 2019 Session Write Up

This session introduces the review and project planning process. The review focuses on successes, barriers and lessons for the future drawn from the experience of being a carer in BANES. The project plan responds to the general experience of being a carer and outlines potential ways to improve the wellbeing of carers and cared for.

What Went Well

Carers Centre provided the platform/support necessary (not feeling so isolated, crucially) for carers to be able to take more proactive role

Developing a partnership with my mother's GP surgery

Being on the board of trustees here and on committees

Formed good partnership with GP, through tenacity to gain that partnership

Encourage person-centred care for under-represented groups (particularly LGBT) by getting organisations to explicitly include these groups – if not made visible, people won't engage

Care & Repair –providing equipment –worked with them, all worked –hospital bed worked well

Raised awareness around LGBT issues in relation to living with dementia via media – TV, radio &c. Via Alzheimers Society – asked to share on media
Influence went on to address other minority/under-represented groups (if not represented, some people might not reach out at all)

Alzheimer's Society influenced to update their info to specifically suit LGBT carers/caree community (which has extended to other minority communities)
Dementia Action Alliance work followed on from Alzheimers – presented at events, conferences

Involved with supportive parents for special children – regarding education/statements &c.

- Our GP responds quickly
- Red flagged with reception
- With Stroke Association did Bath access
- Helped RUH with their ‘VALUES’ – around the hospital

Social Work Project at Bath University – where are the social workers now, several years down the line?

Trialled an Alexa for Somerset Social Services – led to ways they could use it for other people

Involvement in social work courses – one of the best things I did

Involved with a group in the council (Sirona) – give the carers voice

What Could Have Been Better?

How do people register as a vulnerable adult and who should know? –waste collection –police –water –council –&c.

Housing a lack of suitable provision to share housing

Don’t know before you go somewhere if it is physically accessible

Understanding, support, respect from my employer of my full-time caring role

Joined up services that deliver what it says on the tin

Keeping the same social worker

Keeping the same GP – if you move not too far but out of their ‘area’

Assisted refuse collection – doesn’t always happen – then they place bin right in the centre of drive

Pharmacy doesn’t dispense repeat prescriptions on time not fully done – keep having to return for individual replenishments

For carers to understand financial assessment and how that relates to services available

How the money works

If a person approaching a service doesn't expect to be met with empathy and a personal, caring response they are unlikely to reach out and access the service
This is made worse if a person belongs to a minority group, who may have a previous negative experience accessing services – not seeing themselves represented
Ae is a factor – upbringing and attitude – more elderly might not reach out due to upbringing

Signposted to signposts...
—What services are available? –What do I need? –How do I know what I need or can have?

Visibility of services/support – How do I know what's available to me as a carer?

Relevance of services/support – Has to reflect my age group, minority status, condition of cared for &c.

More proactiveness – Carer has to be the one seeking services/support available – when caring too little time

Bereavement group for carers who have lost the person they cared for

What Can We Learn for the Future?

Carers Centre (or other appropriate nominated organisation) to represent carers at public level meetings to put carers needs to service providers (NHS, local authority, central government, and other statutory authorities)

Support carers who could represent key issues to attend meetings to put case studies forwards (i.e. provide care for their cared-for)

Chronology of care support needed

Videos (short) online explaining care/support and 'how to' videos

Consult/survey carers on priority issues new carers could address in importance

Carers Centre – being proactive in helping carers understand the care assessment and financial assessment system for providing care support i.e. points = level of money available for care for person

Carers Centre should be promoted – contact between carers is important in service influence context
Contact between carers – buddying was positive – means of providing that more personal approach in same way. Even over phone, opportunity to share is important and productive – people whoa aren't carers don't normally get it. – Carers Centre administered self-support group

Carer-produced/influenced 'manual' covering all the different means of accessing/navigating services – financial/social services/bereavement services &c...
Ask carers from their experience e.g. top 20 important services with named organisations, links &c.
Chronology of accessing/arranging services – sorting out order things need to get done so that you as a carer don't have to work it out for yourself

Representative group of carers with different needs present during key conversations with service providers to highlight the importance of these different factors that might not otherwise be considered

Accountability

To make carer's lives easier, give them more time to do other things, keep them healthier (both the carer and the cared for person) physically and mentally.
This will have an impact financially on the carer, as well as the service providers.

Specific goals

To make the information about accessing all the different services relevant to a carer clear, coherent, comprehensive, and easily accessible.
(Don't want to repeat work that has already been done)

Measurables

The info is all up to date and doesn't need to be added to

Survey of carers using the info – intermittently

Initial questions giving to carers when they start using the information, further on asking ‘has your awareness of/access to services improved?’

Question: Have you used the things in the info pack
Question: Quality of life
Question: Have you found anything you previously didn’t find out?
Question: Do you feel supported and know where to go for help?
Question: When you contacted the services, what was your experience?

Feedback is crucial (cross section of needs represented in a group)

Financial impact on service providers

Feedback from different groups amongst carers

Individuals

Service providers
Carers
Carers Centre
Students – business studies & social care &c.
Key providers – local trusts, statutory bodies, health services, local authorities
University staff – researchers/funding
Links from Carers Centre who may already have this info e.g. Virgin Care with customer’s groups &c.
Local health services
Social care services
Representative for health and social care from local council

Carers' Voice Group Thursday 26th September 2019 Session Write Up

Preliminary comments

There is an issue in providing an intro / help to new carers since each person's journey into becoming a carer is so varied.

E.g. the experience of a parent carer vs. a partner carer is very different.

The realisation that you are a carer creeps up on you. Not immediately obvious to the person despite circumstances.

Volunteers to help navigate the system of services used by carers would be helpful – different 'experts' to signpost to particular things.

Email/information overload – 'barrage' of emails from various different organisations for carers who involve themselves.

The Ladder of Co-production

Reflecting on experience as carers in relation to the ladder of co-production

The ladder of co-production is a simple tool listing different 'rungs' which equate to different levels of engagement and involvement, ranging from Coercion at the very bottom rung, to fully fledged Co-production at the top. In this instance, the ladder is used as a conversation prompt to reflect on the ways in which carers typically experience involvement in different organisations and projects.

Examples of Coercion

Arranging hospital appointments, process does not account for personal circumstances of carers.

Typically, carers are invited to meetings at the end of a process, where all the key decisions have already been made – this is common of NHS meetings. Tokenistic gesture to 'involve' community

Recently, the BSW CCG plan to combine into single CCG held a meeting of this sort.

The Digital NHS project left carers with an ill feeling due to how the process ran.

Certain carers are willing to attend / participate but time is very limited – so if decisions are already made or the information presented is waffle, this leaves people likely to disengage from processes in the future.

Parent carers new SEND website – ‘consultants’ were fitted into the launch event (consulted when the project is already launching!) – inconsiderate of carers’ time and situation.

Often not told the result of consultation for different projects.

Not viewed as equal to professionals – tick box exercise to involve community.

E.g. typical guideline of 17 double side pages from NHS – filled with repetitive info, no valuable info.

Lack of respect / patronising towards carers.

‘Professional’ / academic experience / knowledge still not equivalent to the actual lived experience of being a carer.

‘Hidden knowledge’ exists across the carer community – volunteer experts to signpost the system would be useful.

‘Experts by experience’ as a phrase resonates with the experience of carers.

Carers often intimidated by professionals – tend to shut up and not bring your experience to bear – also since relying on them, don’t want to antagonise them – fighting for what you need results in being labelled as ‘difficult’ – applies with parents speaking to school staff, dealing with council &c.

Having to argue to make your point heard is exhausting, especially alongside carer duties.

Can become obsequious to service providers despite paying taxes towards those services.

Further up the ladder

Carer’s Centre, Stroke Association, MS service group are all good at honouring ‘experts by experience’, ‘official’ services are not so good at this.

Charitable organisations do a better job – they listen and treat carers with respect.

Primary services tend to work within their given remit / act as though they know what’s best for you.

Professionals aren’t going to be able to properly understand carers without having their own experience of it – professionals should be checking in – asking ‘how about you?’

Professionals aren’t all going to be able to gain a proper understanding of what it is to be a carer but they can go some way towards understanding.

GP contact often depends on the individual doctor – struck for time / don’t want to hear because of the work resulting from the conversation.

Ambassador / volunteer carer coordinator in GP surgeries to keep track of number of carers coming in has been attempted so far.

Volunteer Experts / Advisor Volunteers

In order to meet the goals already identified during this process – specifically to facilitate the creation of a resource by carers for carers to make their lives and responsibilities a bit easier – volunteer ‘experts by experience’ from the carer community would have a crucial role.

Look at the skillset of volunteers from the carer community, who could take on these roles, refer to further set of volunteers to vet their experience and ability.

Local organisations have attempted to compile manuals but this proved to be too great a task – needs to be an ongoing project in any case as relevant information will change.

Compassionate BANES – Compassionate Communities strategy – volunteers to signpost potentially available through that project.

Frome Compassionate Communities currently being showcased – advising BANES on the Compassionate Communities strategy.

Alongside advisors, an online resource is needed – volunteers in the community who can pass on details.

An individual carer produced an online programme for carers – asked to trial via Digital Panel – website produced by Annette (jugglingcare.com) – course for early stage carers.

Representative Group

Discussions in the last session devised that a representative group of carers able to keep in touch with relevant organisations would be a way to begin building up a consistent presence of carers and their perspectives in important decision making processes.

The Carers Voice panel at BANES Carers Centre is already involved in various organisations – Health Watch, Virgin etc. – this group could potentially act as the representative group to present carers' perspectives to organisations.

Presenting the perspective of carers comes with the risk of the process being mere consultation – how can we ensure that the contribution of representative carers is valued and has an impact (is acted upon)?

Representatives need to make their personal experience explicit in meetings – 'I'm a carer with lots of contact with other carers – here's what my experience tells me is important'.

Lead from personal experience – share personal stories – put into context for groups who might have a limited experience of what it really is to be a carer. [In co-productive processes, the personal experience and stories of community members are very valuable and it should be possible for these narratives to inform decisions.]

Carers often become disillusioned by the familiar process of tokenistic involvement, so when initially consulted they can be thinking a bit too negatively to productively engage right away.

Carers Voice group on journey to become advocates for carers.

Representative group could begin by being built on Carers Voice group, acting as consistent presence with different organisations that members are already involved with. This could create a space for carers' perspective/experience/stories to be considered in all/more decision making, also coordinating with wider carer community as somebody to listen to them who genuinely understands. Relaying carer's perspective upwards to organisations, and outwards to the 'carer community'.

Manual

The resource produced by and for carers would take the form of some sort of 'manual'. A resource which compiles information and advice relevant to carers.

All Together BANES – Compassionate Communities BANES project – coordinated by 3SG, an organisation dedicated to linking up 3rd sector organisations in Bath and NE Somerset.

To avoid reinventing the wheel, the timeline for creating the manual needs to account for All Together BANES strategy since volunteer coordinators/experts might be sourced through that effort.

[In general, the efforts of this project to empower carers to have greater influence over the services that affect them should avoid replicating the activity of existing projects, and instead seek to create partnerships.]

Key components of the manual are a publicly accessible resource – online and as hard copies – alongside volunteer experts who can advise and signpost.

All Together BANES can be linked to via all different organisations – parish councils etc. – 'go here to find out more, and you can call...'.

Community made up of lots of different organisations/communities – training them all up/involving them over time can enable them to refer people to the right services – Carer Friendly Communities.

Carer Friendly Communities – spreading knowledge, how are carers better supported in their own communities – being able to know how to help/where to refer people to.

A manual could potentially dovetail into the Carers' Centre digital strategy.

Carers supported *in their community* to continue their caring role – a goal to work towards.

People becoming 'carer aware' in communities.

Wider community awareness can help facilitate signposting/ongoing use and updating of the manual.

In the longer term, the manual project can be combined into other strategies.

Public-level Meetings

Discussing the presence and representation of carers at relevant public-level meetings.

Generally there is not enough notice given ahead of public-level meetings for carers to make time to attend/know it's worth their time.

Cost of attending is prohibitive – such as transport costs.

Lip service of mere consultation – what is the point of attending if that's al that's going to come of it?

Carers' Centre staff can't attend to represent so carers would have to go – replacement care from other careers could be provided – perhaps facilitated through the Compassionate Communities/All Together BANES strategy – a time banking style set up to coordinate this could work?

The Carers' Café is a good example of carer-led activities, carers taking the lead over time and requiring less support from the Carers' Centre.

Carers showcasing co-productive approach – why it is more effective/efficient – this can help get further funding etc.

Diversity

Marginalised groups need to be involved consistently as they are typically more reticent about getting involved – for the same reasons as carers in general feel disillusioned by the usual processes of ‘mere consultation’, in addition to the particular challenges faced due to their marginalised status

Diversity strategies recognised by Carers’ Centre – engaging with relevant organisations to ensure diversity/inclusion.

Need to engage with people how they want to be engaged with – whether that’s specific to BAME groups or accounting for social anxiety.

Applied for funding to promote inclusivity via digital participation (digital strategy).

Same people tend to attend at the Carers’ Centre, which is useful to have consistency but it will be very valuable to have the means for wider ongoing engagement that is inclusive of marginalised groups.

Carers’ Voice Group Thursday 17th October 2019 Session Write Up

Accountable – How is our project good for the community and why do we want to pursue it?

We want to create a carers manual, by carers for carers. This will benefit the community by:

- Making information easily accessible in one place.
- Reducing the isolation of carers.
- Removing some anxiety around missing important information.
- Ensuring that information is reliable and up to date.
- Gaps and errors can be identified by users, and their feedback will be acted upon – this will change the experience of carers by reassuring and empowering them to be heard, and removing some of the stress associated with being a carer.
- Making information accessible at a time and place that works *for you* – putting the carer back in control of their life in some respect, and avoids the chance encounter of being in the right place at the right time in order to receive useful information.
- Informing the decisions of carers, which will be empowering.
- Allowing users of the manual to see the whole picture in one place.

The manual must be a directory targeted at both navigating social care services for the cared for person, and support services for carers themselves. These two aims will compliment each other – caring for the carers in order to support their caregiving.

The manual needs to

- Account for people without computer access.
- Integrate into existing technologies to avoid creating unnecessary work or creating multiple overlapping destinations for carers to visit.

Specific – What are the specific goals we want to achieve through this project?

We want to:

- Clearly identify aims and objectives.
- Increase awareness amongst GPs.
- Create a clear path to find help and access support.
- Use layman's language so that it makes sense to everyone.
- Ensure that everybody knows about it.
- Provide access to more services and support.
- Improve connectivity or community. It will help to link other carers with similar situations.
- Highlight gaps in services and unmet needs.
- Reach out to the most isolated carers and keep them in control.
- Increase awareness in the community.
- Reassure carers.
- Raise the profile of carers and caregiving.
- Minimise bureaucracy, making it quick and easy to update and keep relevant. It needs to avoid becoming obsolete so that people don't lose faith and confidence in the manual.
- Encourage people to use the manual/services (particularly those who are currently inactive).
- Lead to empowerment of the people who use the manual/services.
- Users become advocates to other people.
- Take a degree of pressure off of carers.
- Make information comprehensively accessible to carers.
- Provide access to more services and support.

Measure – How will we know we have achieved our goals? How will we measure our success?

- We will measure the success of our goals via:
- Number of visits to the website.
- Conducting regular surveys.
- Witness testimonial in effective conversations.
- Having an online rating system – 'Was this information helpful?'
- Increase in referrals to specific services – asking those services to provide re-

ports of referrals from the manual on a regular basis.

- GPs will be consistently signposting (new?) carers to the manual.
- Feedback from carers and other professionals, family and community.
- Running reviews.
- Follow up on other agencies' input when carers approach them through the information provided in the manual.
- A shift of more care in the community and a reduction in admissions.
- A reduction in carer frustration and stress (unclear how to measure)
- Overhearing people on bus talking about it.
- See advertising on bus tickets, car park tickets, prescription drug bags and so on.
- Outcome based accountability.
- Pop ups on the website at 'end' of enquiring.
- Posted feedback forms.
- Phone calls to request feedback at a certain interval.
- The manual needs to be ongoing and constantly managed (by team/feedback from users etc.) to keep it current.

Individuals – Who do we need to include in the project? Whose help or advice do we need? Do we need to involve anyone else in our decision making?

- Faith based groups
- Doctors and GP surgeries
- Pharmacies
- Carers
- Families
- Community champions
- Swallows
- St Monica's Trust
- St John's Foundation
- BANES Carers Centre
- The BANES area
- Local charitable services – organisations covering BANES, local or national
- Digital panel
- All Together BANES
- 3SG
- Bath University
- RUH (Ageing Challenge)

- BANES Parents Carers Voice
- Rice Clinic
- Community associations e.g. Saltford
- Village agents and their support
- Virgin Care
- Experts by experience – suggestions from carers who should be included that are particularly helpful

Logistics – What are the logical steps necessary to achieve our goal? What is our step by step plan?

Goal: Creating and launching the manual

1. Asking carers what should and shouldn't be included.
2. Researching what already exists – are there similar resources that exist – are they helpful and why?
3. What are the common websites used by carers?
4. Check with carers if they want this through things like Care Time, e bulletin, the carers Christmas party and so on.
5. Carers Cafés discussions – involving the wider carer community.
6. Devise a clear statement of aims – avoid mission creep.
7. Meet with the council to clarify their current plans.
8. Talk to 3SG about the overall project.
9. Meet with Virgin Care (this will be necessary at various stages).
10. Group works out costs and sources of funding.
11. Project incorporated into Digital Panel discussion.
12. Discussion at Parent Carers Voice meeting.
13. Discussion with NHS UK.
14. Presence in care homes linked with home carers to access those home carers who visit.
15. Manual created and launched.

Economics – How will our goal be funded?

Existing funding streams and relevant budgets will be identified through the process outlined above.

Yes – Are we able to say 'Yes, we feel able to commit to this goal'? Yes!

Carers’ Voice Group Thursday 14th November 2019 Session Write Up

Facilitator training for review process

Using the review tool, we practiced running through the review process so that it can be used independently by the group. The group can use the review tool to monitor the progress of the project coming out of these sessions, or to be used to guide conversations in meetings or at events relevant to the project.

Roleplaying using the tool, we reviewed the Carer’s Voice group with different members in the group taking on the role of facilitator. The outcomes of the review were:

What went well? Why?

‘Lunch’ – Makes carers feel valued for their time and input.

‘Carer’s stamp’ – enables Carers’ Centre to badge changes / new initiatives etc. that have been discussed as ‘carer involved’ etc. and not just ‘done to’ carers by unnamed person / organisation

Great social aspect – opportunity to meet others that you may not usually meet

Validation of feelings when others express the same thing

Puts carers in the driving seat

Visiting speakers

O.B.A. – outcomes based assessments, accountability

Improves what the Carers’ Centre offers carers

Opportunity for carers to meet to share thoughts, ideas and suggestions

Not a lone voice

Voice more focused on new tool production

Carers’ Voice a success!

Great lunch!

What could have gone better? Why?

More inclusion and linking with other agencies / providers

Handovers for key staff could have been better to make sure carers felt valued and Carers’ Voice important

Senior staff and trustees should be involved in the Carers’ Voice group

Appeared at the beginning to be a closed group. I wanted to be involved, but felt like I needed to be invited. Didn’t realise I could invite myself

Attendance by CEO, chief executive, trustee dwindled

The risk of ‘drowning carers out’. If they have felt in over their head with information on particular consultations and start to feel unworthy of attending the group

More Carers’ Voice in the definition of outcome based assessment

Open and encourage more members to be aware of and participate in the Carers’ Voice group

Stopped for a time because there wasn’t a participation officer

What can we learn for the future?

Learning the ability to build bridges between silos

Invite various speakers to come and visit the Carers’ Centre

Publicise C.V. programme to stimulate more interest and attendance

Make the upcoming speakers known in advance and make it explicit that carers can come to just one meeting if that is what they are interested in. This could encourage more carers to get involved

Raise profile of Carers' Voice

Clear information on what has been happening in the group

Provide feedback for carers' participation e.g. on completion of a project or if their involvement has created change

Wider participation of carers needed

Advertise success

Alison could be asked to become involved with the group

Asking carers if they know anyone who could provide a beneficial visit or talk to Carers' Voice

Application of tools

After going through the review process, reflections on the role and responsibilities of the facilitator position, and looking at other tools, discussion proceeded to cover different aspects of the project plan so far devised in sessions:

Involving the wider community

Care Time can be used to publicise programme with key topics / speakers to invite people to come along, able to see in advance what's relevant to them.

Article about Carers' Voice in Care Time to share what's been done, and what future plans are.

Carers' Café may tend to have focus on things like dementia, Carers' Voice would probably have focus on things like CCG – 'widening the box' through meetings / discussions at the Carers' Café e.g. 'See it my Way' with RUH – contact with hospital to create relationship and maintain presence / acknowledge carers and the value of the Carers' Centre – benefits of this particular community.

Widening the topics covered in talks / bringing in different focuses and tools creates more relevancy for different people. Different value proposition beyond offering breaks and trips to carers – means more people will be part of community as participating in the community will be of more value to them, along with an increasing variety of people.

Opportunity to use Carers' Voice to build on and create links with wider community

Medical institutions

There can be what seems to be an instinctive resistance from medical institutions to involving Carers' Centre and carers.

Hospital struggles to have consistent link with community, or even with certain groups among their own staff – it is always an uphill struggle to form a relationship with the hospital.

Making small achievements / small wins that add up is important.

Presence of carers at key meetings

Carers' representation at meetings through presence of Carers' Voice members – don't want to take on that burden of responsibility – capacity for coming up with ideas is feasible, doesn't necessarily need to be delegated – person can reach out asking for replacement when necessary.

Enough people are already involved in different initiatives, can use that existing involvement to share opportunities for influence / build on existing involvement. ('Dig where you stand' – don't create new obligations)

Carer presence raises profile, and this is important, but can't guarantee presence/commitment – not able to make full commitment.

Key organisations don’t appreciate why carers can’t make full commitment – don’t accommodate them and their responsibilities.

Parent Carers’ Voice charter could be adapted – a statement with key information to serve as guidance for organisations which work with carers on how to understand their situation and account for it.

Carers' Voice Group Thursday 5th December 2019 Session Write Up

In the final session with the Carers' Voice group, we took an explicit focus on health and social care services in BANES. The aim for the session was to create a project plan outlining how and when the group would take steps to become active in shaping these services. This discussion was underpinned by the in depth discussions conducted in previous sessions throughout the project, which covered a wide range of aspects of the carer experience.

Initial discussion – what are our priorities in Health and Social Care Services?

Appropriate appointments at hospitals

E.g. early morning appointments / late at night – up crack of dawn or care for person exhausted

Means of finding time for appointment – booking system / service

Waiting time – time restrictions – conditions such as continence / anxiety / need to take medication – need to stick to time slot and account for these situations

In the appointment – need to make comfortable

For carer – stress of handling cared for person – account for this

For the cared for person – need to account for particular condition e.g. near sighted/hard of hearing – need to account for this in way of giving advice / information – if the cared for person is unable to take in the advice given, for whatever reason, the appointment will be less effective

Joining knowledge between GP surgeries / RUH / between departments at RUH – being able to have same treatment experience at all

Notes on carer / cared for situation provided – on system / linked between institutions

Speaking to receptionist to schedule

Consequences of experience of access apps on carers – no means to communicate this – increases agency / gives permission

Undermines purpose of appointments if carer is too busy worrying / accounting for other challenges in appointment experience – ineffective if not paying attention to these issues

Ineffective service provision if not accounting for these issues / experiences

Integrated care records coming into effect soon – can include notes on this

Currently dependent on individual professionals to account for these issues – conversation with particular GP etc.

Way Ahead Care provider account for district nurse visits etc. – can apply this elsewhere

Are there service providers who are doing this well already? Can they support?

Way of letting GP know, for instance

Don't provide solutions without involvement of carers because solution won't be appropriate

Ability to choose convenient times

Phone calls vs letters to book appropriate appointments

What is the current commitment to carers from important organisations? What is the baseline we're working from?

Carers' Charter provides Accountable statement (project intention) for plan – RUH

Integrated Care Record (ICR) in process – need to influence – invite Virgin ICR personnel to discuss

Home visits also pertinent

Focus on ICR and how to influence

Project Plan

Project intention

Carers should be involved in service design process to influence appointments process – it will make a positive impact because:

Will save time for carers and professionals, avoid common situation of recounting situation and needs each time at an appointment

Keep things simple and succinct for appointees and professionals

Account for factors which impede process – provide practical recommendations to improve

Improving scheduling and conduct of appointments to account for additional needs will:

Be mutually beneficial / less attrition / less rescheduling / more successful meetings

Give everyone the best chance for a successful outcome, professionals and patients, aware that everyone has their own individual needs and situation

Shifting perspective to that of the patient – carers and cared for (training etc. would be the next steps in process – increasing awareness)

The carers and cared for are the only ones who know the real consequences which extend beyond the appointment

Better prepared professionals

Financial gain, reducing costs for institutions over time

Specific Goal

Making appointments work for carers

Individuals

ICR project team

Appointments secretary (or equivalent / relevant person to this position)

Carers' Voice Group – chief admin officer at hospital

The Carers' Centre

Relevant people recommended from conversations

RUH Carers' Charter team

RUH directors / board

Healthwatch

Virgin Care

Patient Care Experience team

Wider carer community

Patient Advice Liaison Service

Project Plan

1. **February meeting** Invite Healthwatch to meeting to share plans and find out relevant contacts
2. **Between February/April meetings** Contact people recommended by Healthwatch – find key personnel and invite to Carer's Voice meeting in April
3. **April meeting** Persons relevant to appointment experience service design in attendance
4. Clarify next steps including who to speak to in the future
5. **Between April/June meetings** Host a discussion among the Carers' Voice Group – devise a flexible action plan informed by conversation(s) with project personnel

6. Ongoing reviews of plan created out of April meeting
7. **June meeting and beyond** Further meetings with relevant organisations and reviewing action plan based on those conversations. Process will be ongoing – with continual input from carers / Carers' Voice group and continued reviews to recognise and celebrate progress will inform ongoing plans and record learnings
8. Carers' Voice group will continue to be recognised as a significant organisation doing what its name implies – representing the experience and expertise of carers and the cared for, improving services for individual carers / cared for and caring community at large