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# Public engagement to gather public and patient feedback about developing the Kent & Medway Care Record

October - January 2019



## Summary

In October 2018, Engage was commissioned to undertake targeted engagement with public and patient communities from across Kent and Medway, to gather feedback about the developing model and options for the Kent & Medway Care Record.

The aim of this work was to:

- To increase awareness of the Kent & Medway Care Record using digital communication methods
- To engage targeted sections of the general public across Kent and Medway and explore their thoughts and ideas about the concept of KMCR and what the public / patient might find useful to have included.
- To generate a pool of informed and interested members of the public to create an engagement resource for the project as it moves forward.

A total of **211 people** from seldom heard communities were engaged, through these activities.

This sample size, based on the current estimated population size of Kent and Medway, gives a 90% confidence level with a 6% margin of error. However, when undertaking such targeted outreach engagement we don't only work on statistical measures but also in terms of saturation, reaching high levels of repetition in public and patient feedback.

We heard repetitive themes across all the target groups. These themes were:

- Vast majority of people supported the concept of joining up health and social care records. The majority of people assumed it was already in place
- A belief that this will improve the experience of patients
- A belief that it will improve care
- A belief that it will improve efficiency and speed of healthcare access
- Concerns about confidentiality and levels of permissions to data
- Concerns about security of the system
- Concerns about its affordability and deliverability
- Support for patients being able to access their records

This allows us to conclude with confidence that our sample is representative of the views of the wider population of Kent and Medway.

In addition to these common themes, there were also some unique issues raised:

- Concerns around mental health records being seen by others, for example by social care services.
- Concerns about clinical language, translation and accessibility for people for whom English is not a first language, are disabled, or with limited access to internet.
- Concerns from parents about access to child's records, particularly in divorce/ parental custody situations.

There were some common questions the public and patients would like considered further:

- Who will put the historical data into the new system?
- What is the longer term potential for this system to link with others, both within and beyond the health and social care system?
- Could data records be used for research?



- Could the care records support use of care plans?
- Could the care record platform create a virtual communication tool between patient and GP?

## Methodology

Using our framework of seldom heard and protected characteristics groups, along with Kent and Medway census data and insights about health and social care usage, we identified the target groups set out in table 1. These target groups have then been identified within each of the 12 districts of Kent and in Medway, giving a total of 14 visits.

In addition, to compliment this targeted outreach of people within protected characteristics and seldom heard groups, we have also highlighted 10 communities of common interest, around medical conditions, to ensure that a proportion of those engaged will have actively ongoing clinical / social care input and a legitimate interest in changes around how records are shared to support ongoing clinical and social care needs.

Two key methods were used to reach these target populations;

1. **Digital cascade** – sharing information digitally to a wide range of people across Kent & Medway using established networks and databases.
2. **Outreach engagement** – visiting and talking to targeted community groups and using the focused conversation discussion.

Protected Characteristics	General Target group	Tailored Target group	Data Insight that helped us target this group
Age	children and young people	Children under 9 yrs	Children under 9yrs have high levels of non-surgical / emergency use of hospitals. KCC figures (2013-2015) highlight Ashford to be the district projecting the highest 0-19 population growth at 12%.
	Older people	People aged over 50yrs	People over 50, and increasing further in the over 80's, are high users in accessing care in an urgent/ non elective care situation. Under diagnosed dementia predicted future rates of demand on services. The Census 2011 shows that the East Kent Coastal Districts of Dover, Shepway and Thanet currently have the largest proportion of older population across all Kent districts.
	Students	Student population of Canterbury	KCC figures show that Canterbury has an above county average for the 18-24 year old population. This is because of the two university campuses in Canterbury, University of Kent and Christchurch University.
Disability	Physical disability		Census data 2011 highlights that people living in Thanet, are more likely to consider themselves to have a limiting health problem or disability than the average for Kent.
	Mental health		1 in 4 people are thought to have a mental health problem. Evidenced impact on wellbeing and physical health
	Carers Groups		There are an estimated 27,000 carers in Medway and 161,000 in Kent, with around 12% being 'hidden carers' and not accessing support in their caring role.
	People with learning difficulties		Data highlights that people with learning disabilities are more likely to experience repeated admissions to hospital compared to the general population.
Pregnancy and maternity	Postnatal groups	Maternity and Babies	Census data shows the growing population across Kent. Sevenoaks has one of the highest population proportions of 1- 10yr olds.



Race			Data demonstrates that expected levels of Asian and Muslim attendance at hospital is below expected levels. Data indicates significant Asian and Eastern European populations in the Cheriton/ Harbour areas of Folkestone
Community groups in areas of high deprivation	Using Kent census data re indices of deprivation		Data suggests that people from the most deprived areas are 60% more likely to present to A&E. Swale has largest relative increase in deprivation. Medway life expectancy is 8.2yrs for men & 5.8yrs for women lower than the national average in the most deprived areas. North of Dartford, Swanscombe, Gravesend, Northfleet and Swanley are areas with multiple measures of deprivation. (2015 Index of Deprivation)
Inclusion Health groups	substance misusers		Alcohol and substance misuse are a priority identified within the JSNA for Tonbridge and Malling.
	homeless people		KCC data suggests Dartford has some of the highest levels of rough sleepers in Kent. The relationship between poor housing and ill health is well documented
Communities of common interest			Cancer
			Diabetes
			Dementia
			Heart Disease
			Musculoskeletal conditions (ie Fibromyalgia)
			COPD
			Neurological conditions (ie Epilepsy/ Parkinsons)
			Arthritis
Obesity			
Asthma			

Table 1. Engagement plan using framework of protected characteristics, seldom heard groups and common interest groups.

## Awareness raising digital cascade

The first aim of the project was to increase awareness of the Kent & Medway Care Record using digital communication methods. A short awareness raising article was written and shared across a range of networks and newsletters. (See Appendix 1)

Protected Characteristics	General Target group	Tailored Target group	Engagement methods
Age	children and young people	Children under 9 yrs.	Digital cascade via Children’s centres
	Older people	People aged 50+yrs	Digital cascade via Older Peoples forums Digital Cascade via Age UK network
Disability	Physical disability		Digital cascade via Kent and Medway Physical disability forums
	Mental health problems		Digital cascade via Forums
	Carers Groups		Digital cascade via Carers Groups



	People with learning difficulties		Digital cascade via LD partnership Board
Race			Digital cascade via BAME groups

In addition we shared information about the Card Record to people who are generally interested in health.

These routes included databases owned by the following:

- Healthwatch Kent
- Healthwatch Medway
- All 8 Clinical Commissioning Groups
- Kent Community Health Foundation Trust
- East Kent Hospitals
- Darent Valley Hospital
- Maidstone & Tunbridge Wells Hospital
- Virgin Healthcare
- Kent & Medway Sustainability & Transformation Partnership (STP)

## Outreach Engagement

The second aim of the project was to engage targeted sections of the general public across Kent and Medway and explore their thoughts and ideas about the concept of KMCR and what the public / patient might find useful to have included.

These activities were designed to reach the targeted communities set out in table 1.

The main method used to achieve this was a series of outreach engagement visits to community groups, focused on facilitating a focused conversation, using the focused conversation method developed by the Institute of Cultural Affairs (ICA). This conversation allows people to explore things on a rational and emotional level. It is similar to a focus group in that it works with small groups of people, is a facilitated process and is built around a set of predesigned questions prompts. (Appendix 2 & 3)

In addition, a second methodology of a street survey was adopted in Dartford, targeted as having multiple indices of deprivation.

## Quantitative findings

We spoke with 211 people during these targeted outreach visits.

Protected Characteristics	General Target group	Tailored Target group	Engagement methods	Date	Number of people engaged
Age	children and young people	Children under 9 yrs	Outreach engagement visiting Mother and toddler group	4/12/2018	5
	Older people	People aged over 50yrs	Outreach engagement visiting group in DOVER	10/1/2019	10
Disability	Physical disability		Outreach engagement to group at THANET	22/11/2018	6
	Mental health problems		Outreach engagement visiting group in TUNBRIDGE WELLS	28/11/2018	13
	Carers Groups		Outreach engagement visiting group in MAIDSTONE	13/12/2018	10
	People with learning difficulties		Outreach engagement visiting group in GRAVESHAM	19/1/2018	4
Pregnancy and maternity	Postnatal groups	Maternity and Babies	Outreach engagement visiting group in SEVENOAKS	30/11/2018	9
Race			Outreach engagement visiting group in SHEPWAY	14/2/2018	7
community groups in areas of high deprivation	Using Kent census data re indices of deprivation		Street Survey in DARTFORD	24/1/2019	37
			Outreach visit to community group in SWALE	21/11/2018	9
			Outreach visit to community group in MEDWAY	22/1/2019	21
Inclusion Health groups	substance misusers		Outreach visit to group in TONBRIDGE & MALLING	25/1/2019	8
	homeless people		Outreach visit to community group in DARTFORD	30/11/2018	7
Communities of common interest		Cancer	Outreach visit to community group	29/11/2018	11
		Diabetes	Outreach visit to community group	31/1/2019	2

	Dementia	Outreach visit to community group	9/1/2019	9
	Heart Disease	Outreach visit to community group	18/12/2018	4
	Musculoskeletal conditions (ie Fibromyalgia)	Outreach visit to community group	12/1/2019	2
	COPD / Asthma	Outreach visit to community group	7/12/2018	13
	Neurological conditions (ie Epilepsy/ Parkisons)	Outreach visit to community group	23/1/2019	6
	Arthritis	Outreach visit to community group	23/1/2019	9
	Obesity	Outreach visit to community group	11/12/2018	9

## Qualitative findings

We engaged the groups in general discussion about the Kent & Medway Care Record and the sharing of health and social care records. The discussion was structured by a number of open questions.

We have grouped people's comments and responses to each question, into common themes and ranked them in order of the number of times these themes were mentioned. Under each theme heading are some examples of the range and type of comments made during the focused conversations.

## What details struck you about the current situation and the proposed ideas?

### Isn't it already happening?

- It's a great idea
- They'll do it whether I like it or not
- Thought that things were already joined up!
- I didn't realise that the care records were not already shared between health workers
- It seems 'about time' that these care records are put into place
- Surprised that this hasn't always been the case, but based on previous experiences, could explain why communication is slow

### Improving the patients experience

- This just makes sense, will save me having to remember to bring the red book to every appointment
- I go to a London hospital and Canterbury hospital, and see lots of different consultants and it would be great if they were all linked
- I am always repeating my story time and time again
- At the moment, it takes a lot of time and effort to go through relevant medical history
- Just last week I had to go to hospital. They said they would write to my GP as I needed to see the GP to get the repeat prescription. When I went to the surgery, they didn't have any information about it, so I had to traipse around trying to get it sorted. I had to wait a whole week with no medication while I got it sorted out.
- I am 66 years' old and had to give up work 5 years' ago due to repeated infections and fatigue. Transfer of records takes too long and private treatment records appear not to be kept on the patient record. If these records are not kept then medical professionals can end up with only half the story on a patient's health

### Joining up services across the system

- Makes sense in case of emergencies that they can see everything
- Had different person each time I went into the GPs, and every time they have to read your notes. It would be great if this joined up it would be a quicker way of people seeing your history
- It will be positive for care workers to know who to contact if their patients need urgent care.
- I was discharged from hospital and given my paper notes for me to take to my GP. What if I forgot or had lost them?
- Very good for follow up appointments
- It would help us here, as it would mean that we don't have to wait for blood test results to be sent through

- Referrals to Consultants always seems to present a problem with paperwork

### Improvements in care

- Having access to consent, without having to fax the information over will mean its readily accessible
- There are too many medication errors and this should reduce the risks of errors, as medical professionals can check on the system from previous treatments
- Like to think that if they join things up better, it would eliminate possible missed situations, better decisions and reduction in subsequent problems

### Concerns

- How is it all going to be put into place?
- People don't talk to each other so how will this change?
- GP's do not have the time to read an entire file when a patient transfers. I especially understand this in the case of chronic cases

### Increasing speed and efficiency

- Saves waiting for emails from GPs
- It'll save time for both services, staff and patients
- It'll make sharing information so much quicker

## What's your reaction to greater sharing of care records?

### 'It's a brilliant idea'

- Why wouldn't anyone be happy about this? We don't need to hide our health
- It can only be a good thing, I don't think anyone can access my hospital notes, yet it's such a big part of my health
- I've no concerns. Just do it!
- Doesn't bother me, shouldn't be embarrassing
- It will be brilliant for people who are on their own and don't have family to speak on their behalf

### Improve the patient experience

- Will save us having to tell our story over and over again. I had to tell my story 4 times in the same hospital the other day... if they had been able to see historical data, it would have saved so much time and energy on both our parts
- I went into labour for my second child and had to go to a different hospital. My first labour was difficult and I had some medical complications. In labour with my second child they were asking me what had happened in my first labour, but I don't remember the detail, I just remember things from my perspective, in the fear of first labour. It struck me at the time that they were relying on my perspective and had no other medical facts to confirm what I was saying and they used this info to help define how to support me during my second labour.
- I can understand the need for it. My Dad is very poorly and we are repeating his story lots of times to professionals to get the help he needs

- Got to be an improvement on waiting days or weeks for an update letter from my consultant to reach my GP
- I recently had a 2-week delay to my discharge from hospital because I was waiting for the right care package to be arranged for when I got home, if this would help speed things up that you make such a difference
- Like the idea of looking at my own records and seeing the details of blood tests, the more I understand about my situation, the more in control I feel
- Like the idea of it being in real time, so it's always up to date without having to go to a consultant's secretary for typing

### Concerns about who can access the care record

- I think it's a good idea but I would be worried about people seeing things about me that they shouldn't
- Don't want all of the health professionals to see everything
- It's a bit like Big Brother
- Can it become an individual consent – i.e. tick a box to say people can share the information
- Child vulnerability as well as adult vulnerability – how will the care records be applied in this instance?
- I appreciate that people who haven't come across the need for it a shared record, might not be so keen on the idea

### Want to see records more joined up

- My GP needs to know more about me. At the moment, he doesn't have access to all of my mental health records
- Happy for records to reach as wide as possible such as pharmacists having access to it
- Whenever I go to collect my medication, the pharmacist wants to discuss my medication to ensure I am getting on well with it and how I feel. All of this information could be available on the record, which would save both our time
- It would be great if ambulances knew how to treat you because they have your records
- It is vital that hospitals and GPs are better linked
- Good idea. My GP doesn't know half the information he should about me

### What is not covered?

#### Using the Care Record in practice

- What happens in emergency situations – do the paramedics/emergency doctors have time to read and absorb all of the information on the care record?
- If your GP gets a physical letter in the post then at least it flags up an issue and he might actually read it. If it arrives digitally then he might not notice it and then he won't act upon it
- Communications with GPs: specific relevant information, rather than very old history i.e. broken leg when a child, this would not be relevant to a current hospital visit.
- Lack of notes could cause an illness or allergies not being made aware

#### Governance

- Liability and indemnity insurance, how will the record be governed?
- What will happen if there is a breach of data?
- Will the CQC be in charge or NICE?
- What if it goes wrong?
- Who is the point of accountability? Who's overseeing it and who is in charge?

### Concerns about confidentiality

- Who will see the patient's history and how does the system 'know' which elements of the care record to view?
- I would want to give my consent about what people see
- Is this an opt in or an opt out? If so, it should be an opt out (rather like organ donation law in Wales)

### What is the possible potential for this?

- Could it link up with National Insurance numbers, so NHS number and NI number are linked?
- The data should be used for research, having auto-enrolment to research could help to further expand diabetes knowledge (and other diseases)
- In Germany, your health records are linked to your ID card which everyone has to carry with them
- This could be great to support more organ donors and ensure that expressed wishes such as DNR are also highlighted for all care professionals

### Could this help ensure care plans are developed and used?

- A care plan should be developed for each patient at the point of meeting the consultant / GP, this care plan should be part of this app. At the moment care plans get lost in all the paperwork it needs to be prioritised
- Be good if you are allergic to things
- The Lung Foundation did some work with CCGs to create patient record folder, highlighting medication, consultants and specialist and special indicators for patients. But only a limited number of these folders were handed out to patients so it didn't really go anywhere. Would be great if this could pick this idea up.

### Who can access the care record?

- How would private health providers be part of this? Currently they can't get info about their patients from the NHS so they have to repeat tests. They don't know when their patients are admitted to hospital or what treatment they received. So much information and time is wasted
- What happens if I have treatment outside of Kent? What if I go to Yorkshire for example, will the information still be shared? If not, why not? It should be a nationwide care record

### Is it achievable?

- Have they got enough funds?
- Can they do it without f\*\*\*ing it up? IT systems go wrong
- How will this be carried out successfully?

### What about online access?

- I worked with something similar in the States and they found that when they evaluated it low income families were not able to access it, as paying for internet access was low on their priority list

#### Concerns about accuracy

- If this does happen, I can see things getting missed in people notes

### Is the idea based on sound reasons?

#### Overwhelming majority of people asked said 'Yes'

- Absolutely, can't believe they haven't done this already
- Oh, gosh yes, it's so frustrating the way things are at the moment
- The benefits of being linked up outweigh the possible risks
- Things need to change.
- Communication needs improving

#### Not sure

- Depends how much it's going to cost, if millions is it worth it? It's really down to politicians. I might rather we have more nurses. If £100 million how many nurses could that get?

### What parts of the idea do you think are good?

#### Like idea of it being something patients can look at and use

- Really like the idea of having a section, a front page that gives me the names and contact details of all the consultants I am seeing, a kind of quick reference page
- Like the idea of having self-care section, that can be a reference section for me
- Really like the idea of being able to access your own records
- When you are ill in hospital it will be good to have a copy of what has gone on as you might be too ill to remember what happened.
- If it is possible to have access to the care record, it would help patients to be involved in personal care and having more control over the treatment
- This could help patients to feel more empowered and independent
- Staff will need to be trained in how to write notes if the public are going to be able to see them easier, at the moment they don't write them to be understood by the public

#### A way of communicating

- We have to wait so long for organisations to talk to each other currently before we can get the next part of our treatment
- Currently, lots of patients e.g. in care homes, or based on experiences from carers, have their records completed via 'pen to paper', limiting the communication between the carer and the district nurse

- I am a Carer for a Dementia patient. It would make a huge difference to me and the patient. Currently I leave messages for the District Nurse on the patient's pin board in her house. I have no way to communicate with the District Nurse or other health professionals about my patient

### Time efficient

- If the care records are in one place, it reduces time and individuals do not even need to think or worry about re-explaining cases again.
- Will be good for health care professionals e.g. care workers
- Safeguarding issues could be picked up more quickly.

## What parts of the idea do you think are bad?

### Concerns about confidentiality

- Could it stop people telling their GP things as they don't want them recorded for all professionals to see?
- Who will see the information?
- What if people who do not need to know become aware of the patient's care record e.g. receptionists or friends of patients?
- Linking with other issues e.g. will mental health be on the record, and if so, who will have access to this? Could this be discriminatory with regard to linking to other medical concerns?
- What about sharing information about me that I might not want to be shared? Can I state which bits can be shared? I might not want everyone to know something personal about me'
- I don't want people gossiping about me and my personal information

### Concerns about a digital platform

- Not everybody has access to the internet. If things are financially tough, paying for internet won't be top of people's list
- How to keep the information safe, it's a big issue for everyone

### Concerns about security

- Could this backfire and you find out that your employer can gain access to your records?
- What about if the system gets hacked? They say it is secure but NASA got hacked so anything can be hacked

## What are the advantages?

### A joined up system

- Could be really valuable if someone had a number of different carers. It could help them coordinate and reduce medication mistakes. Will they have access to the full records, or could they just run a subpage recording their visits and interventions?

- My diabetes nurse can't access the blood results from my oncologist, so I have to take a paper copy along every time, this would be a great way to make this easier
- I had an X-ray at Maidstone but when I want to Medway to see another consultant that had to take another X-ray, it's crazy waste of patient and hospital time doing things twice. Hope this could stop all that.
- My consultant might make changes to my medication, but there is no communication between GP and consultant, so I end up being the messenger.
- Could reduce the amount of questions you get asked in hospital
- If you are a paramedic, you may want access to it – especially around allergies.
- Less chance of a security breach if it's all held centrally and secure rather than lots of smaller different places
- Think it's important that information is regularly updated on the system and make sure the system is secure
- Will our hospital passports be put on the system? Some of us have passports with Darent Valley hospital for people with learning disability to let people know about our needs

### A more efficient communication system

- You'll only need to tell your story once
- It will reduce form filling
- I know that social services are struggling at the moment so if this can free up time for their staff that would be great
- Sometimes referral letters don't arrive in time for appointments. GPs have to phone hospitals. This takes time and takes up appointment slots
- My Dad went to hospital and was told to see his GP a week later. He went to the GP and the notes hadn't arrived yet from the hospital so he couldn't get the treatment he needed. Wastes appointment slot for the GP
- Stop waiting for information to come to consultants – would speed up treatment hugely

### Improving patients experience

- You could use the record to show others and gather more opinions and have them able to review each other
- Each time I need to go back to A&E it will mean they can quickly see my history and just help me get straight to the ward I need to be on without waiting around and telling my story over and over.
- Co-morbidity groups can receive better treatment e.g. Alzheimer's and Dementia patients going for a routine operation will require alternative care. Being aware of specialist treatment from the care records.
- Improve the effectiveness of the consultant meetings as most of this is taking the history of the patient
- My wife was allergic to Penicillin. It was on her GP records. We had to go to hospital and the nurse was trying to give her an injection. My wife asked what it was for but the nurse brushed her off saying 'we know what we are doing'. My wife insisted and said she was allergic to Penicillin. Nurse said, 'Good job you told us as we could have killed you'. Surely the Care Record would help in these situations?

### Ability to view your own records

- Self-care option sounds great, to have personalised advice in one place from the team that know you best.

- If I am traveling out of the country, will I be able to access my notes and get the right help if I need to use a different hospital?

### Future potential for further joining up of the wider health and social care system

- Could this link with other providers and community groups to enable the patient to get further benefits, kind of like linking up with social prescribing?
- Could this link with benefits agency so that they can do your assessments more efficiently and more accurately?!
- Personal preferences can be managed also e.g. they could see my preference between hospital and home care

## What are the disadvantages?

The public were equally concerned about confidentiality and security.

### Confidentiality

- Possible that people who don't need to see your records are able to get access
- Will I have to sign something to say I don't want certain people to access my notes, could this be overridden?
- Will opting out be easy? If so, what will be the alternative for me if there are no longer any paper records?
- It might be that the neighbour you don't get on with is a nurse on a ward and can now get access to all your records
- Sharing information – can people at different hospitals around the country have access to it? This is the case for a few of the complex high level care patients who use hospitals around the country.
- Would Health care assistants/ambulance services/111 have access to it?
- I'm not sure I would want social services knowing everything?
- What if my child was genuinely accident prone or we are in hospital regularly for her condition. Social services might see that and get in touch

### Security

- What if the whole thing crashes?
- Needs to be safety checked to stop people abusing the system
- With all the stories you hear about cyber security and breaches in data privacy, do I really want all my records in one place?
- How easy it is for hackers to get into the system.
- How safe is the system going to be?
- The NHS computer was hacked just last year

### Deliverability

- A lack of funding to see the whole thing through and it's left in more of a mess than it currently is
- IT projects don't have a great track record in the NHS, they are always bigger, more overspent and slower than they predict, love the idea, but will they ever be able to make it work?

## What new questions emerged?

### Questions about extent of integration across health and social care

- Could district nurses link into this?
- I go to a London Hospital with my child. The paperwork never follows me in time so they trust me when I say we need this medication and they give it to me based on what I tell them even though it's not licensed for children. How will this new system link with hospitals outside of Kent?
- How will you work out all the Border issues, I live in Maidstone and I'm registered with GP in Medway and use Maidstone hospital
- How far will it extend? Are health care assistants classed as health professionals? Will they be able to see it? should they be allowed? What about Early Help workers? Are they included?
- Will 111 be part of this? It takes so long to go through all the questions but if they had some record of you that would cut down the time
- It was confirmed that SECAmb do not have access to RiO, the electronic patient records system used by secondary Mental Health care (so presumably ambulance crews may not have access to potentially important info about the patient's Mental health).
- Which professionals need to know: vulnerable school children: can the school nurse know, or the social worker? Easy for these individuals to slip through the net.
- Will drug addiction recovery residential places have access to the information?
- Would Locums have access to your record as well? How would that be regulated?
- How would London hospitals link with it? Lots of Medway and Kent residents travel to London for treatment
- Will it link to my Lifeline?
- Are KIMS Hospital going to be part of it?
- How will the voluntary sector be involved with this. For example staff at Day Centres know the attendees very well and notice changes in their well being. They could be an important source of information for GPs and the patient records. Equally they could implement some of the well being treatment needed for these patients if they were connected to the Care Record.

### Questions about access permissions

- Will there be a grading system, to enable you to have some control over who can have open access to the notes?
- How will you make sure that people are giving informed consent, what if they don't understand something that's put in front of them to sign when they are ill?
- Could you have alerts like you do with the bank, so that when someone trying to sign into your notes you get to see how and where from?
- Will there be a passcode for people to access the notes?
- What if I have access to my notes but don't close the app properly, could someone else pick up my phone and see my details?
- What levels of worker will be able to see my notes, when I sign up to this, will I be able to give permission to differing levels of people around access?
- Will there be a patient opt out option?
- What about people with no fixed address? Would it work for them?
- Will it make it easier when you move house as the care record could travel with you?

### Questions about levels of data stored on the care record

- How will the system identify what should be shared and to whom?
- What will they be able to know and what will not go on the records?
- You say the professional would only be able to see the bits of my record that is relevant to them, but how does the system know which bits are relevant? For example, are my migraines linked to my eating disorder and is that linked to the stomach pain?
- Will the receptionist be able to read my record? Some receptionists are triaging people now. I don't want them to see my notes
- How will we know that they (professional) won't read more than they should
- Do allergies come up on the record?
- Do not resuscitate and other healthcare wishes – will these be written down in the record?
- I was asked to bring all my medication to an appointment, this is easily forgotten and so having this on the record will be a big advantage
- How can the different diseases be categorised and thus who can have access to these records – how will this be carried out?
- What about mental health, there might be some reluctant for people to have their mental health detailed for all and sundry to see?

### Questions about possible future use

- Will insurance companies be able to look at this to help them in their work?
- Could this be a portal for virtual contact with your GP
- If social care is involved in this, it could be really powerful way of supporting young people who are at risk or involved in safeguarding. Could bring all professionals together, possibly including teachers, could have really big impact.
- Will drugs companies have access to this?
- Will the data be used to plan more research?
- Could families in need of help use this system to gain support without having to go around each agency telling the traumatic story over and over?
- Can we take the care record with us when visiting Bulgaria? So if we are taken ill they can share with professionals in Bulgaria?
- Could the benefits agency be linked to this to help with applications and getting a better insight into long term conditions / disabilities
- Could the care record have a visual map of what services are available where, as all these recent changes are confusing?

### Questions around access to family members care records

- Will I be able to see my child's notes until they are 18? At what point will they be able to withhold my ability to see their notes?
- What about in the event of a child's notes, when there has been a difficult divorce, would I be able to stop fathers having access to their child's notes? What if you don't want the father to know where the mother and child are, how would this link into court judgements?
- Will I be able to see my husband's notes, and will he be able to see mine?
- Will I be able to give my son / daughter permission to see my notes to help them make decisions about my care?



**Questions about patient access**

- Could there be some interaction, so that your GP / other healthcare professional can see that you are following any agreed self-care plan, and give you support to continue and / or update the self-care programme?
- Future check ups – can medical professionals and patients have some information about medication to jog their memory e.g. information for appointments 6 months in the future can be easily forgotten so this could be put on the record i.e. “remember to bring X to your appointment

**Questions about interpreters/ language barriers**

- The hospital is not always being aware of the communication needs of a patient when they are referred into one of their services. There seems to be inconsistencies in the information being included in the referral from GPs. Could the Care Record be a key part of addressing this?
- Could accessibility adjustments be built into the digital platform, so that I can adjust it to my needs, which can fluctuate with my condition?
- Could the record highlight that after I have had a seizure I can’t communicate quickly and to wait for me to respond rather than talk on without allowing me time?

**Questions about funding and delivering the project**

- Who is going to pay for it? Private investors or tax payers and sold off on the cheap?
- GPs are really overloaded. How will they have the time to create the KMCR? Who will actually have to transfer your record onto the KMCR? Will they actually have time to do it?
- Does it have a back up system if it fails?
- Will they get rid of the children red books, if this system comes in, I like the red books

**Dartford street survey**

A different approach was taken in Dartford. In the more urban areas to the north of Dartford, including the towns of Swanscombe, Gravesend, Northfleet and Swanley, there are areas with multiple measures of deprivation. To reach people in these areas we attended Dartford market and spoke to people as they shopped at the market. We spoke to 37 people, of whom 15 were male and 22 were female.

**People identified that they lived in the following postcode areas:**

DA1	Dartford, Crayford, Barnes Cray
DA2	Dartford (east), Stone, Wilmington, Bean, Hawley, Darent
DA3	Longfield, Hartley, New Ash Green, New Barn, Fawkham
DA5	Bexley, Bexley Village, Blendon, Albany Park, Joyden's Wood
DA6	Bexleyheath, Upton
DA7	Bexleyheath (north), Barnehurst
DA8	Erith, Northumberland Heath, Slade Green
DA9	Greenhithe, Stone
DA10	Swanscombe, Ebbsfleet
DA11	Gravesend (west), Northfleet
DA12	Gravesend (east), Chalk, Shorne, Cobham
Outside of Kent/Medway	
BA2, BR8, SE26	Bath area, Swanley area, Sydenham/Crystal Palace area



The demographic profile of this sample was:

1st language	
English	36
Other	1
BSL	

Consider themselves disabled	
Yes	7
No	29
Not say	1

Age	
Under 16	1
25-34	3
35-59	11
60-74	15
75+	7

Ethnicity	
English / Welsh / Scottish /	32
Any other White background	1
Any Other Mixed / multiple ethnic	2
Caribbean	1
Any other ethnic background	1

A carer	
Yes	5
No	32

Sexual orientation	
Heterosexual	35
Not Say	2

A simple survey asked people if they thought a shared care record was a good idea. 36 of the 37 people we spoke to liked the idea.

However, there were some people who shared some reservations

- *It's good but risky in this day and age – people pinching your ID etc.*
- *Yes, if everyone knows how to use the system.*
- *Need the right people to set it up.*
- *Good if it's implemented and policed properly.*

When asked what they thought the advantages might be of a shared care record some clear themes emerged, listed in order of frequency of mention;

Increasing speed and efficiency (11 mentions)

- *Speed of accessibility to records will lead to saving time*
- *Easily accessible wherever you are*
- *Quickly accessible*
- *Availability of records wherever and whenever you need them*
- *Quick information saves lives. Everyone can see relevant information about me.*
- *Reduces the time delays that you get with letters*
- *Easy access to patients' individual needs.*

Joining up services across the system (9 mentions)

- *Professionals are meant to work together so access is important and sharing is vital*
- *It could speed up treatment and ensure GP's prescribes appropriately with updated information*
- *GP's don't know what's going on if they haven't got all the information*
- *Definitely agree because of my recent experience of going between 2 hospitals and needing me to tell them what I was there for*
- *It will mean a better continuity of care and treatment across the board*

- *I had my mum in hospital suffering from Parkinson's Disease and for all her carers (Dr's Nurses etc) to know what's been decided quickly would ease her struggle.*
- *The list of medication people to take is good to be shared with everyone looking after them*
- *Everyone knows what's going on*

#### Improving the patients experience (7 mentions)

- *I can't always remember things so it would make my life so much easier*
- *I have a metal plate and screws in my foot due to an accident, sharing information will mean I won't need to keep telling the same stories each time I go to the hospital*
- *If you tell one person about your health it's good that the next person will know, without telling the same story over and over*

#### Isn't it already happening? (6 mentions)

- *Why isn't this already being done?*
- *Why has it taken so long?*
- *I thought they already did that*
- *Keeps up with progress which is important.*

When asked what they thought the disadvantages might be of a shared care record some clear themes emerged, listed in order of frequency of mention;

#### Confidentiality and levels of access (23 mentions)

- *I am concerned that people seeing my record might gossip about me*
- *Why can't I have the information and give it to who I think should see it*
- *My concerns depend on who has access to them – should not be available to just anybody... limiting access and ensuring inappropriate people do not get access will reduce my concern... not everyone needs to know I have a boil on my bum!*
- *'Big Brother' too many people knowing your business*
- *If you have something to hide and don't want to share*
- *All patients should have access to their own records*
- *Respect patient's wishes especially around records of their mental health.*

#### Security (12 mentions)

- *It needs to be rigorously monitored to ensure accuracy and input not personal assumptions*
- *Data protection, hacking and leaks*
- *ID theft really bothers me*
- *I know it's not easy, but it really does need to be the most secure system. Some things I would find very embarrassing if they got out.*
- *Please make sure it is fit for purpose, is a decent system and won't crash*

#### Concerns about setting it up (12 mentions)

- *Cost of setting it up and I don't want a private company involved in set up*
- *Concerned they'll increase tax to cover the cost*
- *Cost of training people to use it need to be taken into account*
- *Keep it simple – it needs to be easy for people to use and upload information*

## Citizens User Group

The final aim of the project was to generate a pool of informed and interested members of the public to create an engagement resource for the project as it moves forward.

We recruited 9 members of the public to take part in this ongoing work, forming the basis for a citizens' user group, made up of members of the public to be involved in the future development and procurement of the Kent & Medway Care Record.

## Appendix 1: Communication cascade

### The Kent & Medway Care Record is coming..... Do you know about it?

Did you know that the NHS can now legally share your health records with other NHS professionals to enable them to care for you better?

This means that in an emergency, ambulance and hospital staff can read your health notes to help them treat you quickly and efficiently. Recent changes in the law means that all NHS organisations must now legally share information about your care with other professionals to enable this joined up care to happen.

The way in which this is going to be done is called the Kent & Medway Care Record which is a computer system that NHS organisations can view and read to help them plan and deliver the health care that you need. Only registered health and social care professionals can read your records and they can only see the elements that are relevant to their role and the care that they are providing you. For example, a care worker visiting someone at home might be able to see that they have recently been discharged from A&E without having full access to that person's entire medical history. But they would be able to see who to contact to find out more if needed.

The purpose of writing to you today is to ensure you know about it and to let you know that the Care Record should be in place by late 2019.

The system is highly secure and will be carefully monitored. You have the right to opt out of this if you want to. To do so, visit your GP and make your wishes known.

For more information about the Kent & Medway Care Record and other plans to improve health and social care services please visit:

<https://kentandmedway.nhs.uk/latest-news/a-new-shared-care-record-for-kent-and-medway-is-on-the-way/>

The following organisations are currently involved in phase one of the Kent & Medway Care Record

- All 8 Kent and Medway Clinical Commissioning Groups
- Kent County Council & Medway Council
- All 7 main hospitals in Kent & Medway
- Mental health trusts for both adults and children
- Community health services in Kent & Medway including Virgin Care
- Ambulance service
- GPs and GP Federations
- Out of Hours GP services
- Hospices are being invited to be involved as well.

## Appendix 2: Briefing note for focused conversations

The Kent & Medway Care Record

Recent changes in the law means that all NHS organisations must now legally share information about your care with other professionals to enable this joined up care to happen.

### The complex picture in Kent & Medway

There are around **1.8 million citizens** in Kent and Medway. Currently, patient and social care service user records are separately held by all the health and care providers.

- **4 x hospital trusts** - A&E, emergency and elective (planned) surgery, acute stroke services, consultant-led maternity services and inpatient children's services plus a range of specialist services.
  - Dartford and Gravesham NHS Trust- Hospital at Dartford and a range of planned, urgent and community care services from three other sites in the local area – two of which cross into south-east London.
  - East Kent Hospitals University NHS Foundation Trust – Hospitals in Ashford, Margate and Canterbury and outpatient and diagnostic services from two community hospitals in Folkestone and Dover. Range of services in facilities owned by other organisations and runs renal (kidney) services in East Kent, Medway and Maidstone.
  - Medway NHS Foundation Trust - Medway Maritime Hospital in Gillingham and range of surgical specialities, such as the West Kent vascular service.
  - Maidstone and Tunbridge Wells NHS Trust -Hospitals in Maidstone and Tunbridge Wells and a full range of general hospital services and specialist cancer care
- **3 x provider of core community services** providing a total of **13 x community hospitals with 294 community inpatient beds** and stroke rehabilitation beds, intermediate care beds, urgent care, diagnostics, outpatients and minor surgery and community teams including community nurses, health visitors and a range of therapists
  - Kent Community Healthcare CIC (Kent),
  - Medway Community Healthcare CIC (Medway & Kent),
  - Virgin Care (North Kent)
- **2 x providers of community based mental health services;**
  - KMPT - inpatient, outpatient and community mental health services aged 14 and above and forensic mental health, learning disability, substance misuse and a range of specialist services
  - North East London NHS Foundation Trust (NELFT) - for children and young people who have emotional, behavioural or mental health problems
- **249 GP practices**
- around **466 social care** providers.
- **394 dentists**
- **157 opticians**
- more than **335 pharmacies** in primary care
- **2 x Out-of-hours** primary care services
  - Integrated Care 24 (IC24) in East Kent, West Kent, Dartford, Gravesham and Swanley
  - Medway on Call Care (MedOCC) in Medway and Swale.
- **Social care services** provided by local authorities, including home care, meals, transport and home modifications.
- **303 privately run residential and nursing care homes** in Kent, who provide both health and social care.

In addition a number of people travel from outside Kent and Medway to use services in Kent and Medway hospitals. For example, over 20% of the people who are seen at Tunbridge Wells Hospital for planned care are from outside Kent and Medway. There are close working relationships between the Kent acute Trusts and specialist London hospitals, particularly Guy's & St Thomas' NHS Foundation Trust and King's College Hospital NHS Foundation Trust.

So what's the vision?

Vision for the KMCR “Regardless of who employs them, health and care professionals are able to quickly and easily view their patient’s digital records (or relevant components of them) from wherever they are, and without the need to navigate multiple systems, regardless of the local health or care provider who holds them.”

### How will this happen?

The way in which this is going to be done is via the Kent & Medway Care Record which is a computer system that NHS organisations can view and read on a range of devices to help them plan and deliver the health care that you need. Only registered health and social care professionals can read your records and they can only see the elements that are relevant to their role and the care that they are providing you.

For example, a Care worker visiting someone at home might be able to see that they have recently been discharged from A&E without having full access to that person’s entire medical history. But they would be able to see who to contact to find out more if needed.

### What are the planned benefits?

For patients:

- Improved outcomes because care professionals have better data about their condition, needs and wishes.
- Reduced delays in receiving the right care in the right place at the right time, and where applicable quicker discharge because care professionals do not have to wait for information to be received from another care setting
- Improved transitions of care that should avoid having to give their details and history each time.
- Assurance that all care professionals involved are aware of their needs and care plans.
- Access to own care record allowing better self-management supported by information and advice about how they can help themselves.
- Increased control over their personal health information through a consent model that enables them to determine which organisations and care professionals should have access to their records.
- Personal health analytics enabling them to understand their usage of the care system.
- Personalisation of communication preferences e.g. email, letter or SMS.

For health and social care professionals and providers:

- Better integrated care by sharing data for handovers and MDTs; and enabling new models for delivering integrated care.
- Improved safeguarding: ensuring that children and vulnerable adults that are at risk are immediately known as being so and reducing the level of risk
- Improved quality of clinical and professional decision making: taking into account all relevant information, especially in complex cases.
- Reduced care costs through: avoiding repeated tests and unnecessary treatment; more effective use of out-of-hospital care packages, reducing pressure on emergency care; shorter hospital stays through multi-agency discharge planning; more effective medication reconciliation.
- Quicker and more efficient communication between care organisations
- More efficient workflows: enabling visibility of workflows between care professionals.
- Assurance that care is provided consistently, safely and in accordance with the needs and wishes of the individual.

### What is the Governance for the Care Record?

The basis for sharing information for direct care is General Data Protection Regulation Article 9(2)(h) and Article 9(3). The Kent and Medway Care Record will enable health and social care organisations to meet the statutory ‘duty to share’ set out in the Health and Social Care Act 2012 /2015. Care providers do not need the consent of the patient to access relevant information about the patient or to share it with those who provide (or support the provision of) direct care to the patient if all of the following are met.

### Next steps (anything else to add?)

Your feedback on the proposed KMCR will be taken back to the reference Group.



The development of the KMCR requirements will be led by a Citizen User Group and the Clinical Reference Group.

For more information about the Kent & Medway Care Record and other plans to improve health and social care services please visit:

<https://kentandmedway.nhs.uk/latest-news/a-new-shared-care-record-for-kent-and-medway-is-on-the-way/>

## Appendix 3: Structured focused conversations

### **Objective questions:**

What details strike you about the current situation and the proposed idea?  
What's your reaction to greater sharing of your care records?  
What is not covered in the idea?

### **Reflective questions:**

Is this idea based on sound reasons for change?  
What parts of the idea do you think are good?  
What parts don't you agree with? Why?

### **Interpretive questions:**

What are the advantages of ensuring records are more accessible?  
What are the disadvantages?  
What new questions have emerged for you?