

HEALTH OVERVIEW AND SCRUTINY COMMITTEE

Thursday, 4th March, 2021

10.00 am

Online





AGENDA

HEALTH OVERVIEW AND SCRUTINY COMMITTEE

**Thursday, 4th March, 2021, at 10.00 am
Online**

Ask for: **Kay Goldsmith**
Telephone: **03000 416512**

Membership

- Conservative (11): Mr P Bartlett (Chairman), Mrs P M Beresford, Mr A H T Bowles, Mr N J D Chard, Mrs L Game, Ms S Hamilton, Mr P W A Lake, Mr K Pugh (Vice-Chairman), Mr D L Brazier and Mr A R Hills
- Liberal Democrat (1) Mr D S Daley
- Labour (1): Ms K Constantine
- District/Borough Representatives (4): Councillor J Howes, Cllr K Maskell, Cllr S Mochrie-Cox and Councillor P Rolfe

UNRESTRICTED ITEMS

(During these items the meeting is likely to be open to the public)

Item	Timings*
1. Apologies and substitutes	10:00
2. Declarations of Interests by Members in items on the Agenda for this meeting.	
3. Minutes from the meeting held on 27 January 2021 (Pages 1 - 6)	
4. Covid-19 and winter response 2020-21 - Update (Pages 7 - 18)	10:05
5. Improving care for people living with dementia and complex needs, across Kent and Medway (Pages 19 - 70)	10:35
6. Urgent Care Review Programme - Swale	11:05

There will be a verbal update from the Kent and Medway CCG at the meeting.

7. Medway Foundation Trust - CQC inspection (written item) 11:25

A supplementary paper will be published in due course.

8. Work Programme (Pages 77 - 80)
9. Date of next programmed meeting - Tuesday 8 June 2021

EXEMPT ITEMS

(At the time of preparing the agenda there were no exempt items. During any such items which may arise the meeting is likely NOT to be open to the public)

**Timings are approximate*

Benjamin Watts
General Counsel
03000 416814

24 February 2021

KENT COUNTY COUNCIL**HEALTH OVERVIEW AND SCRUTINY COMMITTEE**

MINUTES of a meeting of the Health Overview and Scrutiny Committee held in the Online on Wednesday, 27 January 2021.

PRESENT: Mr P Bartlett (Chairman), Mrs P M Beresford, Mr A H T Bowles, Mr N J D Chard, Mrs L Game, Ms S Hamilton, Mr P W A Lake, Mr K Pugh (Vice-Chairman), Mr D L Brazier, Mrs S V Hohler, Mr D Farrell, Cllr J Howes, Cllr P Rolfe, Cllr S Mochrie-Cox and Cllr K Maskell

ALSO PRESENT: Dr J Allingham and Mr R Goatham

IN ATTENDANCE: Mr A Scott-Clark (Director of Public Health), Dr A Duggal (Deputy Director of Public Health), Mrs K Goldsmith (Research Officer - Overview and Scrutiny) and Mr M Dentten (Democratic Services Officer)

UNRESTRICTED ITEMS**66. Declarations of Interests by Members in items on the Agenda for this meeting.**

(Item 2)

Mr N J D Chard declared that he was a Director of Engaging Kent.

67. Minutes from the meeting held on 24 November 2020

(Item 3)

It was RESOLVED that the minutes of the meeting held on 24 November 2020 were a correct record and they be signed by the Chairman. There were no matters arising.

68. Covid-19 and winter response 2020-21 - Update

(Item 4)

Mrs C Selkirk, Executive Director for Health Improvement, Kent & Medway CCG and Mrs P Wilkins, Chief Nursing Officer, Kent & Medway CCG were in attendance for this item.

1. The Kent and Medway CCG had provided a report with updates on primary and secondary care operations during the pandemic as well as the Covid-19 vaccination programme.
2. Mrs Selkirk gave a verbal overview of the report and an operational update. She began by noting the prolonged and considerable pressure on NHS and social care staff in Kent over the past year and commended their exemplary work. The latest Covid-19 fatality statistics were outlined, following the report's timeframe, it was confirmed that in excess of 400 people had died between 17 January and 27 January 2021. The staff absence rate was confirmed at 5%, it was noted that not all absences were directly related to Covid-19. Mrs Selkirk confirmed that elective surgery had been halted and that a Phase 4 plan, to

prepare for the recommencement of elective surgery, would be produced in the weeks following the meeting. The Committee was informed that critical care transfers to services outside of Kent and Medway had taken place, Mrs Selkirk noted that repatriation plans had been developed to support patients returning home from these services. It was added that in recent weeks Kent and Medway had given mutual aide to other areas experiencing increased service pressure. The Armed Forces were thanked for providing staff to support operations, which had alleviated hospital staff and permitted an expanded workforce on Intensive Care Units.

3. Mrs Wilkins provided a verbal update on the Covid-19 vaccination programme in Kent and Medway. She emphasised the unprecedented scale of the programme, detailed the programme timetable to that point and reassured the Committee that individuals in all nine priority groups would be vaccinated. It was confirmed that pharmacy-based vaccination would begin as of 29 January. Members were reminded that vaccination data was published every Thursday. Mrs Wilkins confirmed that 127,000 people had received a vaccine in Kent and Medway as of 17 January and that 411,000 people in the top priority groups would be vaccinated by the end of February 2021.
4. Dr Allingham gave a verbal overview of the vaccine programme from the primary care perspective. He addressed the inconsistencies in the vaccine rollout and confirmed that there had been delays in the Weald and Hoo Peninsula caused by the requirement for large, restriction compliant vaccine hub facilities. Dr Allingham reassured the Committee that there had been extremely low levels of vaccine wastage and that GPs had administered vaccines in care homes directly.
5. Dr Allingham delivered a verbal update on primary care business-as-usual operations during the third national lockdown. He confirmed that there had been no reduction in demand, in contrast to the first national lockdown which had seen a sizable reduction. It was noted that the combination of regular business-as-usual demand and the vaccine programme had placed primary care in Kent under significant strain.
6. The Committee expressed their gratitude to all NHS staff in Kent for their hard work, dedication and commitment to patients throughout the pandemic.
7. Mrs Selkirk, Mrs Wilkins and Dr Allingham responded to comments and questions from the committee, including the following:-
 - a. a Member asked how General Practices had dealt with complaints during the pandemic and what had been done to prevent a future health crisis brought on by unaddressed non-covid illness. Mrs Selkirk emphasised that the public were encouraged not to phone surgeries with vaccine related queries, as this had created increased strain. She gave reassurance that the policies on non-covid illnesses had been clearly outlined and listed. Dr Allingham added that primary care was holding considerable strain to protect secondary care services from becoming overextended. He acknowledged the impact national

announcements had on increasing the volume of inquiries received in primary care;

- b. when asked whether non-NHS community health workers would be vaccinated, Mrs Wilkins cited Chapter 14a of Covid-19: the green book and confirmed that all workers in care homes as well as frontline health and social care workers would be vaccinated, as members of priority groups 1 and 2;
- c. Mrs Selkirk was asked to provide recent mental health statistics and to outline the suicide rate in Kent. She noted the significant challenges faced both domestically and in the workplace by many and agreed to provide further information on mental health in future reports to the Committee;
- d. it was asked whether a 15 minute observation was required following an Oxford/AstraZeneca vaccination. Mrs Wilkins confirmed that a 15 minute observation was not required with the Oxford/AstraZeneca vaccine, though individuals were advised not to drive for 15 minutes following vaccination;
- e. a Member requested an explanation of the rationale behind the halt of Vitamin B12 injections. Dr Allingham was not aware of a blanket ban and explained that Vitamin B12 was prescribed for two reasons: to those with pernicious anaemia, who continued to receive B12 injections, and those with a B12 deficiency, who were being treated with an oral supplement;
- f. a request for rural communities to be considered to a greater extent in the creation of future vaccination hubs was made, given the limits of public transport in certain areas. Mrs Selkirk signposted Members to the Kent and Medway CCG's website, cited as the best source for information on future vaccination hubs. It was noted that vaccinations had been carried out by GPs at the homes of those with significant mobility or health issues;
- g. Mrs Wilkins was asked what measures had been implemented to encourage the training and recruitment of healthcare professionals, with an emphasis on GPs. She confirmed that the creation of the Kent and Medway Medical School had contributed positively to Kent's healthcare training capabilities and noted that staff levels were constantly monitored. The role of healthcare partners beyond the NHS in encouraging recruitment was acknowledged. Dr Allingham added that nationally the number of GPs in training had increased over recent time;
- h. a Member asked what support services had been made available to NHS staff during the pandemic. Mrs Wilkins confirmed that staff had access to mental health support through KMPT's Adult Mental Health service, which included online counselling. She made the Committee

aware of recent central government funding received to support critical care staff and reassured Members that staff requests and feedback were considered in the provision of support. Mrs Wilkins acknowledged that further support would be required; and

- i. the Chair asked whether the CCG had given feedback to central government regarding the nationally generated Covid-19 patient vaccination letter, when the possible impact the letter had on increasing pressure on primary care call lines was considered. Mrs Selkirk and Mrs Wilkins confirmed that feedback had been given and agreed to reiterate the concerns raised, with central government.
8. Dr Allingham gave his reassurance that all registered patients in Kent, belonging to one of the nine priority groups would be vaccinated. The Chair implored members of the public not already registered, to register with their local GP surgery.
 9. It was RESOLVED that the Committee note the report.

69. Dermatology Services Update (Item 5)

Mrs C Selkirk, Executive Director for Health Improvement, Kent & Medway CCG; Mrs P Wilkins, Chief Nursing Officer, Kent & Medway CCG and Mrs N Teesdale, Associate Director of Commissioning, Kent & Medway CCG were in attendance for this item.

1. The Kent and Medway CCG had supplied a report which updated the Committee on the developments and lessons learnt following the suspension of the DMC Healthcare (DMC) North Kent dermatology contract in June 2020.
2. Mrs Teesdale provided a verbal overview of the report and gave a general service update. She confirmed that Dermatology Services had continued throughout the second and third national lockdowns and met current national guidance, 70% of patients had received same-day surgery, whilst 90% received surgery within three weeks. It was noted that face to face and virtual consultations had continued and that patient satisfaction had increased to a rate of 85%. The Committee was informed that the emergency contract given to Sussex Community Dermatology Services (SCDS) had been extended, to provide service stability and bolster patient confidence. Mrs Teesdale reminded Members that a harm review was underway, it was not expected to conclude for some time, pending the completion of patient treatment.
3. Mrs Selkirk was asked how contract decision accountability was governed in Kent and Medway CCG and why there had been a reliance on a lessons learnt approach in analysing contracted services. She noted that Kent and Medway CCG commissioned 100s of successful contracts and that very few required lessons learnt evaluation. It was confirmed that specialist teams dealt with specific services, commissions and contracts, with clinician and patient input

considered in the commissioning process. Mrs Selkirk reassured the Committee that ultimate accountability was held by the CCG's Governing Body and Primary Care Commissioning Committee, that their minutes were publicly available and that qualitative and quantitative data was considered.

4. It was RESOLVED that the Committee note the report.

70. Wheelchair Services Update

(Item 6)

Mrs T Flint, Commissioning Manager, Kent and Medway CCG; Mrs J Sarakbi, Programme Director for Integrated Urgent Care, Lead Commissioner for 999 and 111, Kent and Medway CCG and Mr M Teaney, Service Centre Manager Millbrook Healthcare were in attendance for this item.

1. The Kent and Medway CCG had provided a report with performance updates on commissioned Wheelchair Services, operated by Millbrook Healthcare.
2. Mrs Flint gave a verbal overview of the report and outlined recent performance statistics. She confirmed that service waiting times had continued to fall and that they had met national targets, at an average of 15 weeks, a third of adults had waited 18 weeks in 2018, which had improved to 81% by the end of 2020. The Committee was informed that the service's waiting list had reduced to a third of its peak size. It was noted that despite targets being met, service improvements had continued, this had included the completion of actions recommended following the CCG's last visit. The impact of Covid-19 on the service was addressed, it was confirmed that services had remained open throughout the pandemic.
3. The Chair thanked Kent Healthwatch for their involvement in the scrutiny of the service and identified the overall improvement to Wheelchair Services in Kent.
4. It was RESOLVED that the Committee note the report.

71. Work Programme

(Item 7)

1. The Chair confirmed that Covid-19 and the winter response, 2020-21, would return as an item at the next meeting.
2. It was RESOLVED that, with the addition of the item listed above, the committee's future work programmed be noted.

72. Future meeting dates

(Item 8)

It was RESOLVED that the future Committee meeting dates be noted.

73. Date of next programmed meeting – Thursday 4 March 2021
(Item 9)

It was NOTED that the next meeting of the Committee would be on Thursday 4 March 2021, commencing at 10.00 am.

Item 4: Covid-19 and winter response 2020-21 - update

By: Kay Goldsmith, Scrutiny Research Officer

To: Health Overview and Scrutiny Committee, 4 March 2021

Subject: Covid-19 and winter response 2020-21 - update

Summary: This report invites the Health Overview and Scrutiny Committee to consider the information provided by Kent and Medway CCG.

1) Introduction

- a) The Committee has received updates on the local response to Covid-19 since their July 2020 meeting.
- b) At its last meeting, the Committee asked to understand the impact of the pandemic on the number of mental health referrals at its next meeting.
- c) The Kent and Medway CCG has been invited to attend today's meeting to update the Committee on the response of local services to the continuing covid-19 pandemic and winter pressures.

2) Actions from meeting on 24 November 2020

- a) At its meeting on 24 November 2020, HOSC raised some questions that the CCG took away to answer. Responses to these questions are attached to this report.

3. Recommendation

RECOMMENDED that the Committee consider and note the report.

Background Documents

Kent County Council (2020) '*Health Overview and Scrutiny Committee (22/07/20)*', <https://democracy.kent.gov.uk/ieListDocuments.aspx?CId=112&MId=8496&Ver=4>

Kent County Council (2020) '*Health Overview and Scrutiny Committee (17/09/20)*', <https://democracy.kent.gov.uk/ieListDocuments.aspx?CId=112&MId=8497&Ver=4>

Kent County Council (2020) '*Health Overview and Scrutiny Committee (24/11/20)*', <https://democracy.kent.gov.uk/ieListDocuments.aspx?CId=112&MId=8498&Ver=4>

Kent County Council (2021) '*Health Overview and Scrutiny Committee (27/01/21)*', <https://democracy.kent.gov.uk/ieListDocuments.aspx?CId=112&MId=8499&Ver=4>

Item 4: Covid-19 and winter response 2020-21 - update

Contact Details

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Covid-19 update for Kent Health Overview and Scrutiny Committee – March 2021

Content of this report is accurate for the deadline of paper submissions. Verbal updates will be provided at the committee meeting.

Vaccination programme

In Kent and Medway, the Covid-19 vaccination programme is being delivered from 55 sites:

- 39 GP-led vaccination sites cover Kent and Medway's 42 primary care network areas
- Six hospital hubs, which are vaccinating exclusively health and social care staff, other than Medway Maritime Hospital, which is now open for weekend appointments for patients according to the Joint Committee on Vaccination and Immunisation cohorts one to five
- Three large vaccination sites in Folkestone, Gravesend and Tonbridge – with two more in development in Thanet and Medway
- Seven community pharmacies.

As of 14 February, 430,752 people have been given a first dose Covid-19 vaccine (455,910 vaccines have been given including second doses). Weekly updates of data at NHS system (Kent and Medway) level is issued by NHS England/Improvement:

<https://www.england.nhs.uk/statistics/statistical-work-areas/covid-19-vaccinations/>

In the week leading up to the national target of offering a vaccine to everyone in cohorts one to four by 15 February, we put a number of actions in place to maximise capacity:

- On Thursday, 11 and Friday, 12 February, walk-in appointments were offered at the three large vaccination sites. This was extended through Saturday also at our Gravesend and Tonbridge sites.
- Medway Hospital opened a walk-in service for people aged 70+ and those considered clinically extremely vulnerable which was available from Friday, 12 to Sunday, 14 February to support extra capacity and offer patient choice. Text messages promoting the walk-in service were sent to eligible patients registered with a Medway GP.
- Working with our community provider in Medway and local GP practices, we delivered more than 1,000 vaccines to housebound patients in Medway and Swale from Friday, 12 to Sunday, 14 February. Visits continued the week beginning Monday, 15 February to complete the identified housebound cohort. People who have subsequently been identified as being housebound are also being visited for their first dose vaccination.

The system is confident that appointments have been offered to everyone identified within cohorts one to four, all residents in a care home for older adults and their carers, all those 70 years of age and over, frontline health and social care workers and people on the shielded patient list (those who are clinically extremely vulnerable).

Cohorts five and six

The NHS is now offering vaccination appointments to people in Joint Committee on Vaccination and Immunisation cohorts five and six.

Cohort five is people aged 65 to 69. People in this group will receive a letter from the national booking service and you can book an appointment at one of our large vaccination sites or community pharmacy services.

People in cohort six, those aged 16 to 64 with underlying health conditions (considered clinically vulnerable) and those registered as their carers, will be invited by their GP surgery for a vaccination appointment. To be offered a vaccine as a carer of someone who is considered clinically vulnerable, you must be registered as a carer with your GP.

Inequalities framework

A joint working group has been formed across NHS, public health and council partners to create a targeted action plan which will address inequalities and increase vaccination uptake in people from Black, Asian and ethnic minority communities. This group will also look at how to provide vaccinations to individuals identified as having no abode and those not currently registered with a GP within Kent and Medway.

Current pressure from Covid-19

The NHS across Kent and Medway has seen the level of admissions and infection rates slowly reduce since January and this is a positive indicator that the national lockdown requirements are having an impact. This reduction has been welcomed across the system as the numbers of patients requiring admission to intensive care reduce and the number of Covid positive patients occupying acute hospital beds decrease. Community beds and services remain under significant pressure and we anticipate this will continue for some time.

NHS staff, across all organisations in Kent and Medway, continue to perform at exceptional levels, supporting those affected by the pandemic and the delivery of services for non-Covid patients. As the Kent and Medway system begins to plan our approach to recovery, building on existing workforce initiatives to protect and support the wellbeing of staff is crucial, ensuring plans take into account the need to take annual leave and provide psychological support where required.

The vaccination uptake and programme progress brings further hope that Kent and Medway is now in a stronger position to restart those services which were paused and recover the health service itself, all with a clear system plan.

Deaths linked to Covid-19

The impact of the pandemic on Kent and Medway residents has been significant. As of 21 February in Kent there have been:

- 3,810 deaths within 28 days of a positive test
- 3,969 deaths with Covid-19 recorded on the death certificate

In Medway there have been:

- 720 deaths within 28 days of a positive test
- 700 deaths with Covid-19 recorded on the death certificate

NHS service summaries

Staffing

Staff absences from Covid-19 infection and self-isolation following Test and Trace contact have had an impact on all services from hospitals to ambulance services and general practice. Absence rates on 15 February stood at 2.01 per cent across all Kent and Medway providers with 25 absences due to Test and Trace. There has been an improvement in recent weeks and with significant progress in vaccinating staff it is hoped that staffing absence rates will continue to improve.

HOSPITAL SERVICES

Hospital services have continued to operate under extreme pressure. Although the number of Covid-19 patients has decreased in January through to February, the total level of occupancy remains high across all Trusts. An improving position can be seen from the peak of the first wave, where 600 confirmed Covid positive patients occupied hospital beds, through to the second wave, where 1,200 were seen. Presently across Kent and Medway there are approximately 500 beds occupied by Covid patients.

Critical care

Critical care units across all Kent and Medway hospitals continue to be under extreme pressure, requiring the use of surge beds in each unit to manage demand. However, the need to transfer stable patients from one unit to another has reduced, with units more frequently able to manage within their own internal surge capacity. As at 15 February, the number of critical care beds currently open and staffed, was 124 against the business as usual number of 83.

- Over the last few weeks mutual aid has been offered to other parts of the country that are struggling for critical care capacity. Kent and Medway has received both national and regional praise from NHS England/Improvement for how the system is managing critical care, particularly given the length of time we have been under sustained pressure.

Work continues to repatriate patients back into Kent and Medway, where they have been transferred to other units, as soon as they are well enough. The system has been asked to pilot a regional repatriation process and provide feedback to refine this for other parts of the South East.

A set of principles has been agreed with all providers for managing critical care capacity alongside elective activity, and will continue to build on these to ensure that de-escalation happens appropriately, enabling staff to have more downtime, while ensuring we maintain sufficient capacity for both Covid and non-Covid demand.

We have produced a set of key principles and a prioritisation process in relation to elective surgery and use of intensive therapy unit's crisis surge capacity during the Covid pandemic. This is supported by acute provider chief executive officers and the regional critical care cell and is being implemented from February 2021.

Planned care

The NHS has worked hard to ensure that patients requiring urgent elective surgery have still been treated wherever possible during the last two months. The focus has involved working with all providers of NHS care including acute Trusts and independent sector providers to enable patients to be treated within the timeframes indicated by the Federation of Surgical Specialty Associations.

In order to minimise the impact on intensive therapy unit beds, independent sector providers have refined access criteria to reduce the risk of needing transfer to acute providers. The patients transferred to the

independent sector are patients who require surgery within one month; this enables acute Trusts to operate on patients who require surgery no later than 72 hours.

The need to increase elective surgery as soon as it is safe to do so is widely recognised by the NHS. The system recognises the impact on individual patients of delaying non-Covid treatments and is working with organisations to identify plans to restart services where it is safe to do so. The plans will be in accordance with the decreased need for intensive therapy unit capacity and focused on ensuring patients who have waited the longest amount of time are prioritised. Kent and Medway will be in a position to provide more specific information on this at the next meeting.

Cancer care

Access to urgent cancer diagnostics and treatments continued throughout Wave 2 across all of our acute providers. Some of these services were running at a slightly reduced capacity due to wider system pressures. Cancer screening has also continued throughout Wave 2 for breast, bowel and cervical programmes. In addition, a significant drop in the number of two week wait referrals has not been seen during and coming out of Wave 2 as was seen earlier in the pandemic.

Maternity

Maternity services have continued throughout the pandemic despite pressure on the workforce from Covid-19. Home births were temporarily suspended by all providers on the 31 December 2020. System wide reinstatement occurred on 2 February 2021. All Trusts are currently working on offering testing for partners attending the 20 week scan appointment, and using the national testing service to facilitate this. It is hoped that this will be in place in all Trusts by mid-March.

A&E pressure and ambulance handovers

The urgent and emergency care system is now stabilising following the significant pressures felt by the Accident & Emergency departments and the ambulance service during December and January. Handover delays are now minimal and the patient flow through the Accident & Emergency departments and hospital settings is in a much stronger position so overall performance is on an upward trajectory and the collaborative system working that has been essential to the management of the second wave continues and will be built upon further as the system continues to de-escalate.

Staffing across the urgent and emergency care system is significantly improved and there is very strong uptake of the Covid vaccination which will support the system in the long term.

Following the successful roll out of 111 First phase one, which saw the 111 service having the ability to book patients directly into emergency departments, Kent and Medway CCG is now implementing phase two. Milestones for delivery are currently being agreed with the national team. The CCG continues to actively promote the use of 111 as it was hugely beneficial in supporting wave two and managing patients outside of face to face settings given the full system integration of 111 into all components of the health economy including primary care, urgent treatment centres, mental health, community providers, frailty and end of life pathways.

COMMUNITY SERVICES

Although the pressure and response from all parts of the system have been profound, Kent and Medway Clinical Commissioning Group (CCG) welcomes the efforts made by all partners. In particular community providers continue to be flexible in providing support to patients in community and non-acute settings and this has been very welcome.

A number of organisations continue to support a wide range of patients from the housebound to those being discharged from hospital. In addition Kent Community Healthcare NHS Foundation Trust is playing a significant role in the Covid-19 vaccination programme as the lead co-ordinating organisation for the large scale vaccination sites.

Occupancy at community hospitals remains high, currently at 96 per cent (15 February), and has resulted in the need for additional beds to be opened across two further community hospital sites; many of these beds remain occupied by Covid patients. Frailty services have been expanded within east, north, and west Kent, as well as Medway, to support the increased system demand witnessed. There is also a falls/frailty car in Medway in operation which continues to have a positive impact on avoiding potential admissions into hospital. Targeted redeployment of tier two and tier three staff, to support the increased demand for tier one services has taken place. Support has also been provided to South East Coast Ambulance Service by providing clinical expertise including GPs and senior nurses, who can help with clinical triage using a direct call pathway. Setting up of these wraparound services has ensured admission avoidance, reduction in conveyance and follow-up care where required.

This is an excellent example of an integrated whole system response to support the needs of patients in a much pressurised system.

MENTAL HEALTH SERVICES

In order to support patients, a number of initiatives are in place across Kent and Medway:

- Kent and Medway NHS and Social Care Partnership Trust and North East London NHS Foundation Trust 24/7 crisis lines services moved to 0800 (free-phone numbers) in December 2020 to ensure the cost of calls are not borne by patients.
- Safe Haven sites have continued to operate and have offered both face to face and telephone support during lockdown restrictions.
- Work continues across the system to monitor the increased presentations of people to emergency departments with a primary mental health diagnosis; this will help the system to understand how to improve access and identify collaborative actions to support the acute hospitals. To support this further, development of a clinical model is underway for 111 as the point of entry for mental health crisis pathway.
- In January 2021, a winter project commenced to provide proactive follow up treatment for people who have presented to an acute Trust site with self-harm. Liaison mental health services continue to be available 24/7 at each of the acute Trust sites.

Community mental health team referrals have remained slightly suppressed by approximately 10 per cent since June 2020. Whilst there has not been an increase in numbers, the acuity of symptoms experienced by people referred is much heightened.

Improving Access to Psychological Therapies (IAPT) providers have enhanced their advertising, however they have not seen anticipated activity levels follow. They are all offering online interventions for service users.

Real time Covid demand modelling is forecasting new referrals to rise to around 10-15 per cent above normal rates in the early part of 2021. Ongoing increased demand is likely and will therefore be considered in the next iteration of the modelling.

The Mental Health and Wellbeing Hub website pages are currently being built and will be completed by end of March 2021. As well as providing information for the public, it will also house the mental health offer for both health and social care staff. Also a mail out is being prepared listing sources of help and support and this will go to every household in Kent and Medway to promote services and the website.

Advertising for Release the Pressure, a website to help support individuals with their mental wellbeing, has been increased and a campaign is currently being run on Kent radio.

To note, staff have been redeployed from the community mental health teams for older people to support staffing within care homes. This is to enable proactive discharges from acute hospitals and is very much welcomed by providers.

Children and young people services

As part of the Mental Health Investment Standard 2020/21, there are a number of areas in development to support young people throughout Kent and Medway:

- Crisis Pathways - there has been an investment by North East London NHS Foundation Trust to increase workforce and crisis response including development of out of hospital/home treatment models to meet Long Term Plan (LTP) targets
- Investment in SHOUT text service
- Development and issuing of 75,000 crisis cards issued to schools, Kent Police, primary care and other partner organisations
- Roll out of the Emerge project - a pilot at Maidstone and Darent Valley Hospitals to reach children and young people presenting in Accident & Emergency because of self-harm, suicidal ideation or emotional crisis.

There are also a number of transformation projects within Kent and Medway including:

- 0-25 specialist bereavement service (in procurement)
- Evidence based intensive mentoring for children delivered by Salus in Dartford, Gravesham and Swale to respond to low access rates within the area
- Investment in the established suicide prevention programme
- Unaccompanied asylum seeking children psychological therapies delivered within reception centres and outreach centres
- Programme commissioned to deliver Trauma Informed Approaches training for 1,300 staff, working with children between 18 and 25 years
- Development of a service user-led peer mentoring model, via Young Lives Foundation.

There is also a focus around eating disorder services, with Dr Simon Lundy leading as the Clinical Lead for the CCG. A business case has been developed around Enhanced Care Pathways, Avoidant/Restrictive Food Intake Disorder and First Episode Rapid Early Intervention.

Children and young people community services

Services across the system continue to be delivered virtually in the main, with face to face appointments offered to those risk-assessed as most clinically vulnerable. The biggest challenge remains access to schools for therapy services during the current lockdown period. Referrals across the system have dropped; however modelling suggests there is likely to be a significant increase in March once schools return. Providers have been asked to prepare for this and we continue to monitor the situation. The vaccination programme is being rolled out in special schools and to those parents of children deemed most clinically vulnerable. Significant progress made on actions identified following the 2019 Special Educational Needs and Disabilities inspection in Kent.

Learning disability and autism

Throughout the Covid period the Learning Disability and Autism Programme has continued to function in line with NHS England requirements. The key priority areas are reduction of inpatient hospital activity, completion of Learning Disability Mortality Review and completion of annual health checks which have continued.

In terms of agreed priorities the Learning Disabilities and Autism Programme has made the following progress:

- Learning Disability Mortality Review improvement plan completed - all outstanding reviews completed. The Kent and Medway Learning Tool was shared as good practice across the region.
- Association of Healthcare Communicators Plan - to improve current position agreed with NHS England - the plan improves the Kent Community Healthcare Foundation Trust model to help primary care deliver Association of Healthcare Communicators through the Network Contract Direct Enhanced Service. A new clinical lead is in post, and the Special Educational Needs and Disabilities Plan to deliver Association of Healthcare Communicators to children and young people was agreed, commencing in January.
- Care and Treatment Reviews are compliant and on.
- Children and young people in-patient activity is on target and the improvement plan for adult in-patients has been agreed with NHS England.

During December 2020 there was an increase in the number of people with learning disabilities dying from Covid-19. In response Kent and Medway Clinical Commissioning Group has adapted the local vaccine implementation plan to respond to this health inequality impacting our learning disabled population. Kent and Medway Clinical Commissioning Group agreed to include all adults with learning disabilities who are on the GP learning disability registers in the first phase of the vaccination delivery in order to mitigate health inequalities. There are approximately 9,500 people in Kent and Medway on GP learning disability registers. Adapting the priority list to reflect evidenced local need will not disrupt other vaccination priorities and the CCG will continue to provide the co-ordinating role as the system's command centre liaising with NHS England/Improvement South East. A number of clinical staff from the CCG have been redeployed to support frontline services.

POST-COVID ASSESSMENT SERVICES

As the UK is faced with the prospect of living with Covid-19 for the foreseeable future, protecting those who have been affected by Covid-19 now and in the future is a priority for Kent and Medway Clinical Commissioning Group.

Prevalence rates note that the spread of Covid is highest in areas with increased deprivation/high population and a relatively younger population. Therefore, Kent and Medway's approach to developing a post Covid syndrome assessment services, will be focused on responding to specific differences in our

population and ensuring that the most vulnerable and affected in our community are supported throughout their journey and recovery. Work is moving at pace with a partner to pilot a test of change approach to the introduction of services for patients. It is expected the service will be ready to accept referrals within a matter of weeks. This approach will ensure the service can adapt quickly to reflect the patients who need ongoing support and enable a more comprehensive offer to be developed and rolled out across Kent and Medway.

In terms of understanding the volume of patients, the system is working with NHS England/Improvement to develop a model which will take into account the acuity of Covid patients, the Kent Covid variant and the volume of people who have experienced Covid and Covid-like symptoms.

Kent and Medway will ensure inequalities and variation in service provision are avoided by working closely with colleagues in the design and implementation of services.

Caroline Selkirk
Director of Health Improvement and Chief Operating Officer
Kent and Medway NHS Clinical Commissioning Group

22 February 2021

Kent and Medway CCG

February 2021

The Health Overview and Scrutiny Committee asked for written responses to two questions following the November meeting.

Question 1: Adam Wickings to provide a written update to members regarding Ellenor and the support of service delivering charities.

Response: Ellenor Hospice, like other adult hospices across the Country, received additional financial support during the Covid-19 Pandemic through an earmarked funding mechanism provided nationally.

Question 1: Adam Wickings to provide a written update to members regarding Covid-19 rapid response in Swale:-

Partners across the Medway & Swale system are working together to support patients to remain at home and restrict the use of Medway Maritime Hospital, underpinned by the Local A&E Delivery Board.

As a response to Covid 19 some existing services have been either enhanced or expanded while others have been recently introduced. The following provides some examples of these –

- The Virgincare Rapid Response Team provides a 2 hour response with nursing staff and support workers providing short term intensive nursing, therapeutic support and immediate domiciliary care support for up to 72 hours until before handing over to the Kent Enablement Hospital at Home Service, where necessary.
- Additional support to Rapid Response is being provided by the MedOCC Out of Hours service (MCH) who are supporting the team with advice and guidance, especially with prescribing, enabling patients to have speedier access to prescriptions.
- SECamb crews now have direct access into the Rapid Response Team, providing assurance that patients will be appropriately supported enabling the crews to leave the home and return to supporting other calls within the community.
- Patients at risk of admission are proactively identified by primary care based multidisciplinary teams, coordinated by dedicated MDT coordinators, with health and social care representation, enabling proactive care planning and/or navigation into support services. We have also introduced Integrated Locality Reviews for particularly complex patients with representation from Medway Maritime Hospital Consultant Geriatricians.
- A Paramedic Practitioners home visiting service, managed by Minster Medical Group, is supporting primary care. The Practitioners are able to refer to health or social care services where required.
- A virtual Covid Oximetry@home service is in place to monitor patients with Covid in the community – managed by Minster Medical Group.
- Patients discharged home from Medway Hospital following an episode of Covid are followed up with a 'well being' check in call from Imago Community Navigators 24 hours and 6 weeks post discharge to support access into health, social care or voluntary services if required.
- All nursing, residential and learning disability care homes are aligned to a Primary Care Network supported by community teams for proactive care planning, care management and medication reviews. Each home has a named clinician and a weekly check in call.

Adam Wickings
22nd February 2021

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Item 5: Improving care for people living with dementia and complex health needs, across Kent and Medway

By: Kay Goldsmith, Scrutiny Research Officer

To: Health Overview and Scrutiny Committee, 4 March 2021

Subject: Improving care for people living with dementia and complex health needs, across Kent and Medway

Summary: This report invites the Health Overview and Scrutiny Committee to consider the information provided by Kent and Medway CCG.

The Committee has yet to determine if the proposals constitute a substantial variation of service.

1) Introduction

- a) The support available for individuals living with dementia is provided by adult social services and the NHS. The NHS support includes treatment received through the GP and hospital.¹
- b) If a person has complex health and care needs, the NHS may cover the cost of both types of care above through “NHS continuing healthcare” paid for by the local CCG.²
- c) The NHS Long Term Plan set out the government’s intention for improved support in the community for people living with dementia – “We will go further in improving the care we provide to people with dementia and delirium, whether they are in hospital or at home.”³

2) Background

- a) Prior to the formation of a single CCG in Kent and Medway (in April 2020), West Kent CCG was leading a review into the clinical model of care for dementia patients across the county. HOSC determined that the de-commissioning of the Frank Lloyd Unit in Sittingbourne (that provided specialist support for those with complex needs) was a substantial variation of service.
- b) The Committee was minded to refer the proposal to the Secretary of State for Health and Social Care because it did not feel the closure was in the best interests of the local population.
- c) At the HOSC meeting on 22 July 2020 the Kent and Medway CCG accepted that the decisions made in relation to the Frank Lloyd Unit had not followed due process. It set out its next steps as:

¹ NHS (2018) Dementia, social services and the NHS, <https://www.nhs.uk/conditions/dementia/social-services-and-the-nhs/>

² ibid

³ NHS (2019) NHS Long Term Plan, p.17, <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>

Item 5: Improving care for people living with dementia and complex health needs, across Kent and Medway

- Undertake a full review of current dementia services being provided to this cohort of patients with complex needs.
 - Undertake demand and capacity modelling to better understand the requirements of the Kent and Medway population both now and in the future.
 - Develop a robust 'case for change' for Kent and Medway.
 - Develop options for the future clinical model for this cohort of dementia patients with complex needs, their families and carers, considering a range of factors including clinical quality and outcomes, patient experience, access, workforce, and value for money.
 - Develop options for how and where the new clinical model could be delivered, aligned to national policy and clinical best practice.
 - Ensure public and stakeholder involvement in developing the case for change, the proposed model of care and the options; and consulting on this as appropriate.
 - Continue to engage with HOSC, NHSE/I assurances panel, patients, carers, the public, staff and stakeholders before, during and after consultation.
- d) Following a discussion at the above meeting, HOSC decided not to refer the closure of the Frank Lloyd Unit but it resolved that:
- “the next steps (set out on page 43 of the agenda pack) be noted and that the committee add that the Frank Lloyd unit be kept available until the review is completed. The committee will write to the Secretary of State to express its concern over the process undertaken by the previous CCG, which led to the suspension of the Frank Lloyd unit.”*
- e) The Kent and Medway CCG has been invited to attend today’s meeting to present an update on the above steps. The Committee is scrutinising the proposed new model of care for dementia patients with complex needs and not the future of the Frank Lloyd Unit (though this may feature in the new model).

3) Potential Substantial Variation of Service

- a) The Committee is asked to review whether the proposed new model of care for dementia patients with complex needs constitutes a substantial variation of service.
- b) Where the Committee deems the proposed changes as not being substantial, this shall not prevent the HOSC from reviewing the proposed changes at its discretion and making reports and recommendations to the NHS.

Item 5: Improving care for people living with dementia and complex health needs, across Kent and Medway

3) Recommendation

If the proposed new model of care for dementia patients with complex needs is *substantial*:

RECOMMENDED that:

(a) the Committee deems the proposed new model of care for dementia patients with complex needs to be a substantial variation of service.

(b) Kent and Medway CCG be invited to attend this Committee and present an update at an appropriate meeting once the timescale has been confirmed.

If the proposed new model of care for dementia patients with complex needs is *not substantial*:

RECOMMENDED that:

(a) the Committee does not deem the proposed new model of care for dementia patients with complex needs to be a substantial variation of service.

(b) the report be noted.

Background Documents

None

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**Improving care for people living with dementia and complex health needs,
across Kent and Medway**

Update for the Kent Health Overview and Scrutiny Committee (HOSC)

1. Introduction

NHS Kent and Medway Clinical Commissioning Group (KMCCG) is working with its partners to improve dementia care. There is an increased need for dementia care within the population. This work is being led by senior clinicians under the wider system leadership of the Kent and Medway Mental Health Learning Disability and Autism Improvement Board. We have commissioned additional data to support our understanding of the current use of services and the impact of population increases, as well as recent service changes in line with national best practice.

Our ambition to redesign the model of care for dementia patients, including those with complex needs and challenging behaviour, should be seen in the context of some exciting times ahead for improving mental health services in Kent and Medway. Unprecedented levels of funding and investment are available (£51m) to transform mental health services and support over the next five years. Working together as a health and care system, the Kent and Medway Mental Health Learning Disability and Autism Improvement Board – which includes representation from the NHS, local authorities, social care, and the voluntary and community sector - has big ambitions for mental health services. They include:

- Reducing the need for people to be inappropriately admitted to an acute ward (because of no suitable alternative) by improving community-based support
- Improving psychiatric intensive care for women, by developing and providing this specialist service in Kent and Medway, where currently women needing this very high level of care have to be treated out of county
- Developing specialist dementia services for people with complex needs
- Eradicating outdated and unsafe dormitory wards
- Redesigning community mental health services.

We have a great opportunity over the next five-year period, with investment in and focus on mental health, to provide better mental health services, and care which is fit for the future. Mental health care needs to be more easily accessible, provide a

greater range of services and support, and be more joined-up between all those involved in planning and delivering services.

Our intention is to engage more widely with people in Kent and Medway about their experiences, hopes and ambitions for mental health services in general, later this year but in advance of that, we have undertaken targeted engagement in support of the redesign of the care model for dementia patients which we are presenting to Kent Health Overview and Scrutiny Committee (HOSC) members for their information.

2. Work to date

Our work is based on the principle of providing the right support at the right time to enable patients to remain independent for as long as possible, as well as providing support to their families and carers. Early thinking has suggested that the development of an enhanced community model in partnership with local providers should focus on:

1. Reducing unnecessary admissions to hospital (both acute and mental health)
2. Reducing the length of stay in hospital by providing greater support in other more appropriate settings
3. Increasing supported discharges to appropriate care settings
4. Increasing the number of people with dementia (or suspected dementia) who are supported to return home following hospital discharge
5. Increasing support for carers in the community to enable them to continue with their caring roles
6. Increasing assessments for continuing healthcare conducted outside a hospital setting.

Clinical engagement

A workshop involving clinicians from a variety of backgrounds and specialisms relating to dementia care, was held in December 2019. Clinicians discussed the development of a new model of care identifying the need for:

- A community service, a dementia intensive support service, to strengthen support for people with dementia in their own homes and care homes at a time of crisis, or urgent need, with the aim of avoiding hospital admission and supporting people to remain in their usual environment wherever possible.
- A small number of specialist beds for those complex individuals with dementia and behaviours that challenge and who are not able to be managed in most care or nursing homes. Our demand and capacity work

will take these elements of the model of care into account in determining how many beds are required across Kent and Medway.

Engaging with dementia patients, their carers, families and loved ones

Attached to this update is a report of engagement undertaken between mid-October 2020 and mid-January 2021 to gather the views of people living with dementia, their families and carers, support organisations, health and care staff and the wider public.

This research was carried out to inform proposals to improve dementia care for people living with dementia and complex health needs across Kent and Medway at an early stage. It was preceded by three other pieces of research which will also help us to plan effectively:

1. Community engagement with people living with dementia, their families and carers and voluntary sector volunteers and staff, gathering views on existing support services and any additional needs or perceived 'gaps' in community based services and activities.
2. Engagement with 11 families whose loved ones with dementia and complex care needs were receiving specialist residential care at the Frank Lloyd unit run by Kent and Medway Partnership Trust, funded through Continuing Healthcare. The discussions covered both the broader proposed changes for people living with dementia and complex care needs, but focused mainly on the implications for the patients and their families of relocation to alternative long-term residential care
3. Research funded by the NIHR Applied Research Collaboration Kent, Surrey and Sussex (ARCK KSS) and carried out by the Time for Dementia Research team at Brighton and Sussex Medical School, looking the impact of the Covid-19 lockdown on dementia patients and their carers in Kent, Surrey and Sussex.

Using a variety of methodologies including a public survey, focus groups and patient and carer journals, this engagement shows there is a clear need for more support for families and carers supporting a loved one who has dementia and potentially complex needs. The need for this has been made all the more poignant by the pandemic and the pressure of being locked down with many support and public services having to work remotely. Specific suggestions and ideas were made and there was also praise for services and staff along with tangible ideas for improvement.

Undertaking this engagement activity has given us a strong foundation on which to continue to develop and hone proposals. It offers significant insight into the daily experiences of people with dementia, their carers and loved ones and also shines a light on the challenges faced by staff as they support and care for people with dementia.

3. Next steps

Using the Secretary of State's 'Four Tests' and the additional 'Fifth Test' as guiding principles for this work, we are:

- Undertaking a full review of current dementia services being provided to the cohort of dementia patients in Kent and Medway with complex needs
- Undertaking demand and capacity modelling to better understand the requirements of the Kent and Medway population both now and in the future
- Developing a robust 'case for change' for Kent and Medway
- Developing options for the future clinical model for the cohort of dementia patients with complex needs, their families and carers, considering a range of factors including clinical quality and outcomes, patient experience, access, workforce, and value for money
- Developing options for how and where the new clinical model could be delivered, aligned to national policy, clinical best practice, workforce requirements, accessibility factors, and estate capacity amongst other factors
- Ensuring clinical leadership and public and stakeholder involvement are core in developing the case for change, the proposed model of care and the options; and we plan to consult on these as appropriate
- Continuing to engage with HOSC, NHSEI, patients, carers, the public, staff and stakeholders and will carry on doing so before, during and after consultation.

4. Clinical leadership and oversight

A clinical reference group comprising primary care and secondary care clinicians has been set up to provide clinical leadership and recommendations on the proposed new model of care. Clinical model scoping work has been undertaken on the proposed new Dementia Intensive Support service for this cohort of patients.

Commissioners now want to continue development of a robust case for change, and a proposed new model of care in line with statutory duties, aiming to consult on our plans later in 2021 (subject to COVID-19-related requirements). The CCG is committed to regular engagement and formal consultation with HOSC as part of this process and will ensure that regular updates and briefings are presented to Committee members in line with statutory duties and good practice.

5. Recommendation

The Kent HOSC is asked to:

- Note and comment on the recent work to date and next steps outlined within the paper and the engagement report attached as an appendix to this update.
- Agree an appropriate date for the Kent and Medway CCG to return to HOSC to give a further update on progress on this programme, including sharing the case for change in Kent and Medway and proposed new model of care.

Caroline Selkirk

Executive Director for Health Improvement/Chief Operating Officer

KMCCG

Appendix A - attached

Improving care for people living with dementia and complex health needs, across Kent and Medway, KM CCG engagement report, February 2021

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Kent and Medway
Clinical Commissioning Group

Improving care for people living with dementia and complex health needs, across Kent and Medway

NHS Kent and Medway CCG Engagement Team

February 2021

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2. There was also engagement over the same period with 11 families whose loved ones with dementia and complex care needs were receiving specialist residential care at the Frank Lloyd unit run by Kent and Medway Partnership Trust, funded through Continuing Healthcare. The discussions covered both the broader proposed changes for people living with dementia and complex care needs, but focused mainly on the implications for the patients and their families of relocation to alternative residential care. Feedback covered the following areas:
 - making sure that existing patients and their families were supported through the transition process
 - understanding and responding to the needs of each individual patient
 - involving families and carers in the decision-making processes.
3. During 2020 there was research funded by the [NIHR Applied Research Collaboration Kent, Surrey and Sussex \(ARCK KSS\)](#) and carried out by the Time for Dementia Research team at Brighton and Sussex Medical School looking at how Covid-19 lockdown has affected dementia patients and their carers in Kent, Surrey and Sussex. The interim findings were shared to help inform services as they respond to ongoing pandemic. Please see page 18 for more information.

1.1 Population

Kent and Medway has a diverse population, with pockets of deprivation dotted across the county, with affluent areas across west Kent, densely populated coastal towns with high levels of deprivation and an aging population. The largest number of people from Black Asian and minority ethnic (BAME) populations live in Medway, Dartford, Gravesham and Swanley.

Across Kent and Medway, there is currently an estimated 27,000 people living with dementia. Of these, approximately 15,000 people have mild dementia, 8,750 have moderate dementia and 3,500 have severe dementia. At the moment, two thirds of people with dementia live in their own homes and one third live in care homes. The number of people living with dementia in Kent and Medway is expected to rise to over 38,000 by 2030.

2 Research methodology and response rate

Due to the restrictions that the pandemic brought particularly during lockdown, people are being advised to remain home and maintain social distancing, so engagement with people has had to be carried out in a Covid-safe way.

It was obviously more difficult than usual to reach people, and the response rate to engagement activities is lower than might have been expected pre-Covid. The demands of the pandemic on health and care services meant staff were extremely hard pressed and had less time to respond.

To mitigate the impact on response rates we worked with our colleagues across the NHS to share details of how to be involved through their various staff channels (bulletins, online portals, message groups and staff meetings), with their patient and carer groups, and

foundation trust memberships; and through our partners in local authorities with their staff and residents. As well as publicising the opportunity through our community bulletin which goes to 10,000 individuals and voluntary and community organisations. We also used our social media channels to promote the opportunity to take part and shared details with the media. We also used online surveys and telephone or video calls e.g. Microsoft Teams, Zoom etc.

And by working in partnership with the KMCCG local area patient groups and our community researchers and voluntary and community sector partners with their patient forums, we were able to reach out to people with lived experience as well as to gather the views of the wider community. KMCCG Engagement team developed several ways to engage different groups of people. They were:

- **Patient and carers journals or personal stories** were given to us by eight people with lived experience of dementia, another 12 people sent in personal stories or were interviewed to share their experiences.
- **Eight focus groups** were held with existing voluntary or community support groups. 102 people took part, most of whom had lived experience of supporting someone with dementia either in their family or through their organisation. They took part in video discussions on services and gave views about how to improve care.
- **Online staff survey** was distributed to NHS staff, Care Homes, Domiciliary Care and voluntary and community organisations. There were 70 responses from across all health and care services.
- **Online public survey** had 190 responses from across Kent and Medway including people who may not have direct experience of dementia services
- **11 existing local area patient groups and forums** in which 121 people took part in video discussions and then cascaded the information to their individual networks or groups. Eight were supported by KMCCG with members from PPGs and voluntary and community organisation representatives. Three forums were supported by Engage Kent: older people's forums, disability forum and Mental Health Action Groups.

3 Findings from the Patient and Carer Journal or personal stories

To further understand families and their loved ones experience of living with dementia, a journal was created (Appendix C). The purpose of this journal was for the families to share their thoughts, feelings and emotions of their everyday lives and for us as readers, to appreciate and recognise what their daily life is like. It was also used to record where support had been given or was lacking and any improvements hoped for. Alternatively some people submitted their thoughts by letter or email and others were interviewed.

There were eight journals completed, all by carers, caring for loved ones at home and 12 messages were received from people with their family story, or information on services, or with offers to share their experiences. The journals were completed by carers living across Kent. The age of the carers ranged between 55 and 74 and their loved one tended to be

their mum, dad or husband in some instances it was both parents who were living with dementia.

They shared a little about their loved ones with dementia, who have had interesting and varying lives, from being a retired GP to working in retail or as a labourer, to being a housewife. And their interests range from music and dance, to playing sport, reading and helping others and volunteering.

There were four main themes which were articulated strongly throughout the journals. These strongly suggest there is a need for support for those living with dementia and their families in the community so they can remain safe and well at home; and how health and care services could be improved:

- respite care
- consistency in services
- access to services
- support for carers

3.1 Respite care

This was a strong theme throughout the journals, particularly as the carers were living with their loved ones and with them 24 hours a day, seven days a week.

“To be able to book a range of weekend breaks and/or one or two one week breaks during a year; this will keep me going and I’ll know I’ve got a break coming”

There was concern about what to do if both parents were living with dementia and taking one for an appointment and needing care for the other for a short time in the day.

“I really could do with having someone to sit with either of my parents while I take the other to the doctors or to hospital as that is very difficult. But in these Covid times that is really not possible. I took my Dad for his Covid swab test at the Will Adams Centre today and had to take my mum with me, I still do not know what I am going to do on Monday afternoon with my mum when my Dad has his procedure???”

There were concerns about the stress and strain dementia can put on families, where respite care may be able to resolve some of this.

“In the last 2 years I have found it almost impossible to go away for a night or a weekend. This has created real friction with our daughter, who is worried about me, and angry with her father for basically taking me over as she and I used to go away together regularly – we both miss this.”

And it was noted the importance of the loved one with dementia having a little independence and being given the opportunity to take part in activities without their husband, wife or family.

“I would like there to be more things locally for my husband to do without me so that we both get a break from each other.”

3.2 Consistency of services

There were concerns raised about the how fragmented services supporting people with dementia are and the challenges families face in bringing those together so their loved one is treated holistically.

“The main problem is that services/teams are really fragmented and it is really difficult to find out who is responsible for dealing with what.”

3.3 Access to services

Many people shared experience of the services they used. Many had had strong support from various different service providers: pharmacists, GPs, occupational therapists, social care, carers, specialist diagnostic services, admiral nurses, specialist mental health services, cleaning companies, and a variety of community based support services through voluntary agencies and adult education.

“Carer’s support was brilliant. The most reassuring thing was having a card that said I was a carer and that if I was in an accident that someone would be in trouble! I wasn’t able to make use of many of their services as I could not get away for long enough or I was trying to earn money, but I could take Jeff to one support group which was helpful. They might have been able to help with settling in when we moved but I didn’t know about them in time.

The Parkinsons nurse was a life-saver as so few people seem to understand Parkinsons.

Social services were really helpful when I called up in floods of tears and said I couldn’t cope any longer!”

They also spoke of their difficulties in accessing services: one family spoke of the difficulty of finding services that have a full understanding for the different types of dementia. Others spoke of the difficulties they encountered when the person with dementia was able to mask their need or ‘seem much better than they really were during assessment’, or if they were capable of refusing the services offered and not letting domiciliary carers in to help. Others recorded feeling that access to help was prohibited because they were self-funding so were left to find services themselves.

“Financial assessment done over the phone and they were told they had £500 per month to buy their own care. Outgoings did not consider gardening costs, household repairs, mums hair (one thing she did for herself).

The Care Navigators came to their home – left loads of leaflets and numbers – no follow up.

They left mum to ring everyone, explain the story over and over and get rejected.”

3.4 Support for Carers

When reading the journals, you could feel the stress the family were feeling when caring for their loved one living with dementia and immense strain they are under on a daily basis. One area mentioned was mental wellbeing.

“I do sometimes find it a mental strain rather than a physical one, as I have had to learn a whole new set of life skills, as my husband used to do a lot around the house and a lot of other things which I have to do now.”

“Having both parents suffering from dementia simultaneously has been a nightmare.”

“I’m only 62 now, and I want to live!”

Financial stress and worry was highlighted, particularly in the longer term when full time care is needed.

“my Mum and Dad are not allowed to pay me for doing this as if we are financially assessed it will look like we are trying to take money from the tax man or from a care home should they need to go into one”

“I haven’t mentioned my fears about our finances and having to pay for care in the longer-term.”

4, Focus groups

Due to the pandemic, it was a real challenge to engage with dementia support groups, as many were not meeting physically. Some were meeting virtually, by using Zoom, and some more general support groups agreed to discuss improving dementia care and encourage those with relevant experience to attend. These discussions reflect the experiences of the families who shared their personal stories in their journals and some of the themes are similar.

Table one shows the groups visited and the number of carers and loved ones who attended.

Table 1

Support Group	Number of People spoken to
Carers First	12
Dartford and Swanley Dementia Support Group	20
Forget Me Knots Support Group	18
Gravesend/Safe harbour Dementia Support Group	14
Medway Neurological Network	9
SUNshiners Support Group	6
wHoo Cares Support	5
Swale Community Empowerment Network	18

Community Health Researchers	33
MTW carers focus group	3

The discussions with and the views of people at the support groups, were very similar to those mentioned by the patient/carers and raised in the other groups.

The top four themes were:

- respite care
- health and wellbeing of carers and families
- support services for carers
- care plans

4.1 Respite care

The groups suggested respite care was imperative for carers and families especially the importance of having day care as well as short week/weekend breaks.

“regular respite to ‘recharge the batteries’ would help significantly.”

“There is no support”

“Need time just to go and have a cup of coffee with friends”

“Carers would like a holiday away from caring role”

However, one group discussed whether respite care is unaffordable for some, and the person living with dementia may not want to attend.

The group as a whole agreed that it was not always affordable and in general the cared for did not want to attend anyway.

And the suggestion was to provide an affordable service, which caters for all.

“having affordable day care services with more of a holistic approach to the cared for. Services should not be means tested and should be available to all.”

One person mentioned how important respite care is in a crisis, although it is not readily available when needed.

“Respite services are extremely valuable in times of crisis, especially for carers. These services were said to be difficult to find.”

A concern that was raised was the availability of respite care at short notice, particularly if a carer was taken ill.

“What is available if the main carer became ill and couldn't provide care anymore?”

During the pandemic fewer services are running either online group calls, or by sending activity packs or making phone calls to check on families.

“My husband has definitely missed his Alzheimer’s groups. I wonder if that is why he’s so unmotivated now”

3 days a week, he would have gone to a group and had lunch there. None of them are operating now.

4.2 Health and wellbeing of carers and families

There were concerns raised about the carers’ and the wider families’ health and wellbeing and the effects of looking after their loved one with dementia.

“Caring for them affects me and my family very much. It is a draining job which is like babysitting two toddlers. Their moods can keep changing and I have to adapt to it each and every time.”

“Some days I don’t get time to keep aside for my family. I get so tired that I would just hit the bed and wake the next day. The list is endless and each day we have a different situation at home.”

4.3 Support services for carers

There were mixed feelings about support for carers and it looked like this depended on where in Kent and Medway people live and the service they were seeking support from.

A positive comment was:

“The MCH ‘Dementia Crisis Support Team’ was praised, especially the Admiral Nurses. they were very good, very helpful for us……. We were lucky to get an excellent Admiral Nurse – every family should be allocated an Admiral Nurse.”

Facilitators from the focus groups captured feedback which was not so positive:

“The overall feel from the group was that they did not feel well supported in their carer role.”

“A lot of carers mentioned they had to fight for what they needed, most seem to just accept they have to fight.”

And one of the participants said:

“You have to be bloody minded and fight hard to get the support you need”

People felt there is a need for a single point of access, where people can go for all your information, rather than having to find things out piecemeal.

“There needs to be something similar to a single point of access (a bit like the crisis service). Someone needs to know about the different types of dementia to make sure people are signposted to the right service.”

And the need for a support service to “check in” with families regularly.

“Patients need regular contact i.e. a weekly phone call, rather than waiting for a crisis to happen.”

A suggestion from many of the discussions was to have a list of organisations which offer support and when they available and their contact details. It was highlighted that a directory of service like this would be really helpful; however it would be challenging to keep updated. A route map of what to expect was also suggested as the wealth of written information was too much to understand given at diagnosis.

4.4 Care plans

Discussions about care plans were less positive as there were feelings that not all services were using the plans.

“care plans, devised by multi-disciplinary teams, were only really being provided as part of Secondary Care (dementia care was mainly being provided by GPs)”

And some care plans weren't working due to them not being assigned a care coordinator.

“We do have a care plan and it says that we have a Care Coordinator, but we haven't got one.”

One facilitator shared that the group felt:

“Those that DID have a care plan said that it was not working well because they had NOT been given a care coordinator”

The groups agreed the statement below, is how a care plan should work:

“People diagnosed with dementia (particularly those with moderate or severe dementia) should be given a Care Plan and assigned a 'Care Manager' (not just those receiving Secondary Care). The provider/point of contact of this care plan service should be clearly identified, e.g.GP or MCH or KMPT. Role of Care Pathway Manager/ Care Navigators at Primary Care Network level heading a multi-disciplinary team should be clarified.”

5 Findings from the staff survey

In this survey, the questions were focused on several areas including: personalised care, change in level of needs and staff training and specialist support. We had 70 members of staff respond from across care homes, domiciliary care, hospital trusts, community trusts and voluntary and community organisations. All of the services and organisations we shared the survey with, were affected by the pandemic, which will have affected the response rate.

It should be noted that some questions have been skipped by some people, which means there will not be a 100 per cent response to all questions.

The highest staff response rates are from staff working across east Kent; however we had a good response from all localities, as diagram one shows.

Diagram 1

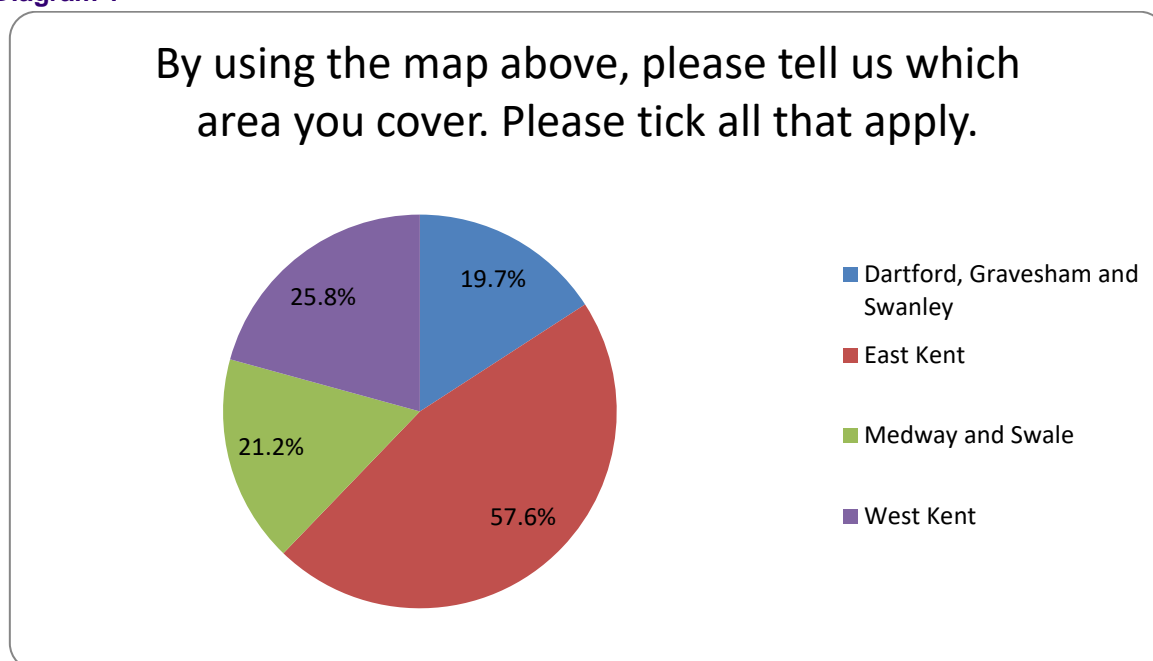


Table two below shows the different organisations the staff are employed by. The 16 responses categorised as “other” included community care, primary care and community organisations.

Table 2

Answer Choice	Response Per Cent	Response Total
1 Acute Trust	9.0	6
2 Community Trust/Community Service	20.9	14
3 Domiciliary Care Services	4.5	3
4 Nursing Home	3.0	2
5 Residential Care Home	6.0	4
6 Secondary Mental Health Services	9.0	6
7 Social Care Service	7.5	5
8 Voluntary and Community Organisation	23.9	16
9 Other (please specify):	23.9	16
answered		67

The survey was carried out in five sections:

- personalised care and the importance of care plans
- changing levels of need

- how to support people in a crisis
- staff training and specialist support
- improving healthcare for people with dementia

5.1 Personalised care and the importance of care plans

The first section asked staff about how a care plan assisted them to care for the person living with dementia.

- 81 per cent of responses from staff felt the care plan helped them to manage any changes in the person's health.
- 25 per cent stated there is a lot of information in the care plans to manage a person's behaviours,
- However 47 per cent say there is information, but only some which is not detailed enough to help them to manage a person's health.

Table three below shows how the staff ranked in order of importance statements suggesting the benefits of a care plan

Table 3

	Answer Choice	Total Score	Overall Rank
1	Patient/resident's dignity is respected	251	1
2	Everyone involved in their care has the same information	197	2
3	We know what the patient responds best to and any triggers which confuse or anger them.	195	3
4	We know of any choices or directions about healthcare given by the patient, their carer or family	164	4
5	We know which medications are being used and current symptoms	108	5

It can be seen that staff feel the main benefit of a care plan is the dignity of the person living with dementia is respected and everyone involved in their care has the same information, and the staff know what the patient responds to best and any triggers which confuse or anger them.

A care plan called '[This is Me](#)' was referred to frequently by carers. It contains details of the person living with dementia and guides and advices services that support them, to take a person centred approach to their care. Please note this frequently came up as a useful tool when talking to carers, or patient groups but some individuals were concerned that it wasn't used sufficiently by staff in residential care.

On the survey, staff were also asked about the support the families receive: 70 per cent of responses felt that families do not receive the help they need to look after themselves, including their own physical and mental health and wellbeing. However, 84 per cent of

respondents felt confident they could signpost families to appropriate services if they needed to.

5.2 Changing levels of need

This section of the survey focussed on services staff uses when a person starts to show signs of being unwell or display challenging behaviours during working hours. When this happens, responses indicated that staff's first point of contact is the local GP (64 per cent), followed by the specialist mental health team (49 per cent) or those they would seek advice and guidance from their line manager, care manager or from a local dementia organisation (33 per cent).

Table four below lists the services staff would go to during working hours:

Table 4

Answer Choice		Response Per Cent	Response Total
1	GP Practice	64.6	42
2	Urgent Treatment Centre	4.6	3
3	Hospital Emergency Department	7.7	5
4	NHS 111	23.1	15
5	Specialist Mental Health Service Team	49.2	32
6	Community Geriatrician/Nursing Service	13.8	9
7	Ambulance Service	16.9	11
8	Other (please specify):	33.8	22

And table five shows the service staff would go to outside of working hours, specifically evenings and weekends.

Table 5

Answer Choice		Response Per Cent	Response Total
1	GP Practice	4.7	3
2	Urgent Treatment Centre	6.3	4
3	Hospital Emergency Department	10.9	7
4	NHS 111	60.9	39
5	Specialist Mental Health Service Team	25.0	16
6	Community Geriatrician/Nursing Service	3.1	2
7	Ambulance Service	25.0	16
8	Other (please specify):	31.3	20

It can be seen that the top four services staff would use outside of working hours are:

- NHS 111 – 61 per cent
- Other – 31 per cent which includes crisis team, rapid response team or Crossroads
- Specialist mental health team – 25 per cent
- Ambulance Service – 25 per cent

5.3 How to support people in a crisis

Question 10 on the survey asked: if there have been occasions where you have been unable to access crisis/urgent support, what has usually happened?

When a member of staff is unable to access crisis support, 67per cent of respondents would send the person to hospital, 22 percent would support them by offering one to one support in the place where they live, or refer them to the rapid response team.

One respondent commented:

“It is very rare to get one to one at home day or night. Night-sits can delay a person going into hospital or a care home. Sometimes its the carer who needs a break as they have had no sleep. The person with dementia has a urine infection, delirium and requires supervision until anti-biotics work. The NHS should block purchase care home beds so that they can be used when the need arises instead of sending people to A/E dept and then assessment can be completed there.”

98 per cent of respondents agree that there is a need for a crisis/urgent care service as you can see from diagram two.

Diagram 2

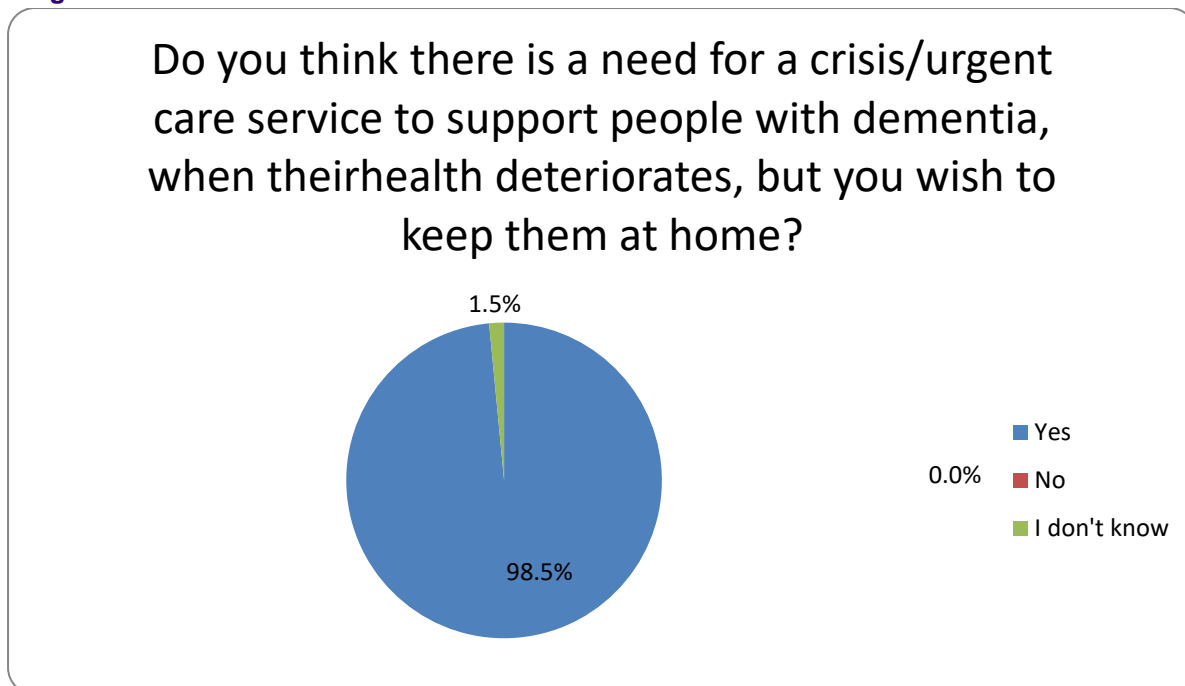


Table six below outlines the hours the respondents feel the service should be available.

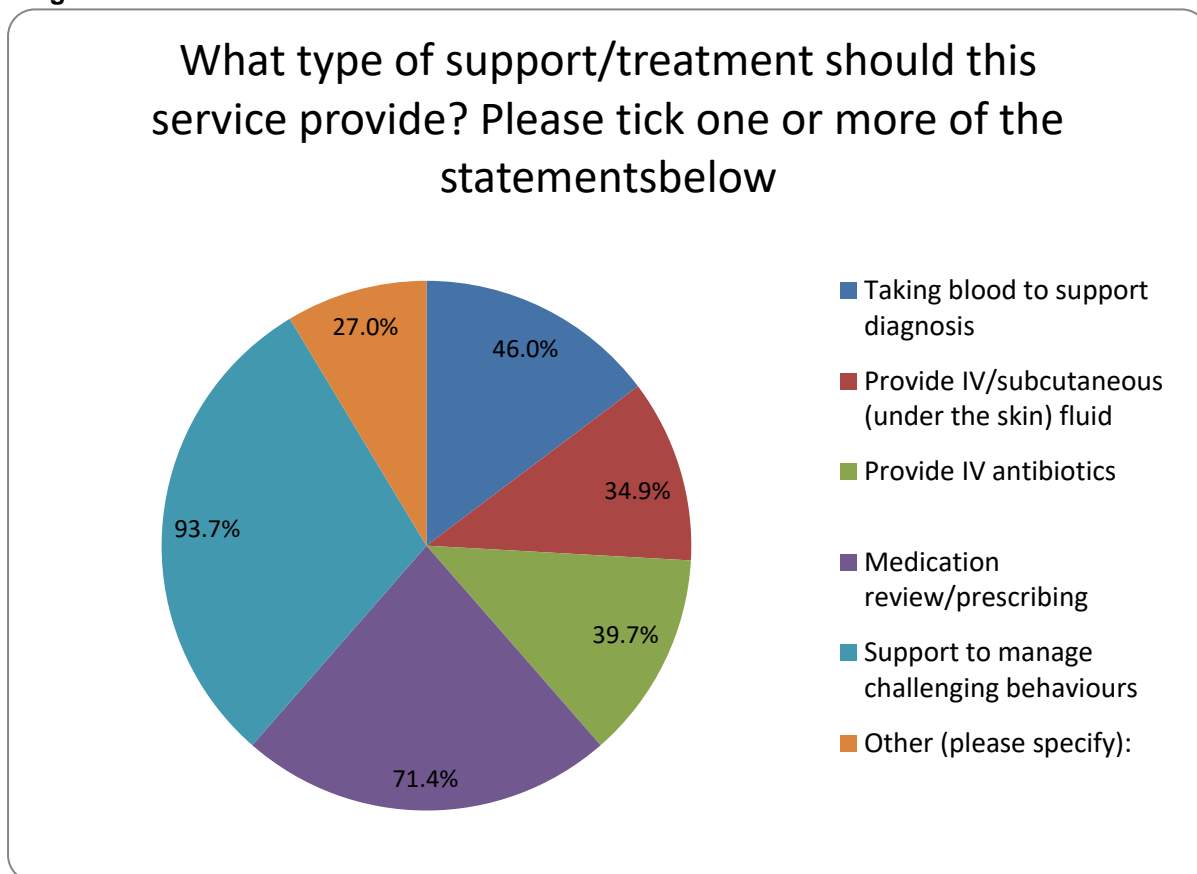
Table 6

Answer Choice		Total Score	Overall Rank
1	Monday to Sunday 24/7	293	1
2	Monday to Sunday 9am-8pm	230	2
3	Monday to Friday 8am-8pm and Saturday and Sunday 9am-5pm	223	3
4	Monday to Sunday 9am-5pm	164	4
5	Monday to Friday 9am-5pm	95	5

Table six shows that respondents feel the service should be available Monday to Sunday 24 hours a day, seven days a week.

The answers to the question ‘what type of support/treatment should this crisis service provide?’ are set out below in diagram three

Diagram 3



Please note respondents could choose more than one aspect so the percentages reflect that.

5.4 Staff training and specialist support

Table 7

Answer Choice		Response Per Cent	Response Total
1	Yes, we are specially trained in dementia care for our patients	54.5	36
2	Yes, we receive training annually	27.3	18
3	Yes, occasionally	19.7	13
4	No, I was trained before I arrived	3.0	2
5	No, there is no time for extra training	3.0	2
6	No, there are not enough staff to release people for training	6.1	4
7	No, we are monitored and supported whilst providing care.	3.0	2
8	Other (please specify):	24.2	16

Table 7 above shows that 54 per cent of respondents are specially trained in dementia care, whilst 27 per cent receive dementia training annually and 24 per cent (other) receive one off training e.g. e-learning, or dementia friends training.

60 per cent of respondents explained they receive training and support on how to manage challenging behaviours and 36 per cent said they don't receive training like this.

For question 16, respondents were asked to tick any services they use to support people living with dementia to stay active and well, the responses are set out in Table 7 below.

Table 8

Answer Choice		Response Per Cent	Response Total
1	GPs	50.0	28
2	Geriatricians	33.9	19
3	Specialist Mental Health Nurses	48.2	27
4	Admiral Nurses	37.5	21
5	Occupational Therapy	46.4	26
6	District Nurses	50.0	28
7	Physiotherapy	44.6	25
8	Voluntary organisations offering patients advocacy or support activities such as Dementia UK, Alheimers Society, Age UK	62.5	35
9	Social Care - advice on support, benefits	48.2	27
10	Other (please specify):	23.2	13

**Please note the overall total is above 70 as people were able to choose more than one service.*

It can be seen 62 per cent of respondents seek support from voluntary and community organisations, 50 per cent speak to the GPs and district nurses, and 48 per cent contact social services and the specialist mental health team.

5.5 Improving healthcare for people with dementia

The final section of the survey asked respondents what they felt would improve health and care for people with dementia, and checked on the difference the pandemic had made.

The top three improvements that were suggested by the respondents are:

- more support, education and help for carers and families (41 per cent)
- respite care (15 per cent)
- more specialist dementia training and education for staff (12 per cent)

The top three greatest challenges identified by respondents prior to the pandemic were:

- carer and family access to support (43 per cent)
- carer breakdown and stress (16 per cent)
- communication and information sharing (8 per cent)

And the top three challenges identified by respondents during the pandemic are:

- access to services (56 per cent)
- social isolation (34 per cent)
- person living with dementia understanding the purpose of personal protective equipment (PPE), hand washing and social distancing (25 per cent)

6 Research on the impact of the pandemic

A recent piece of research by funded by the NIHR Applied Research Collaboration Kent, Surrey and Sussex (ARCK KSS) and carried out by the Time for Dementia Research team at Brighton and Sussex Medical School was shared with us as were the results of a focus group conducted by Maidstone, Tunbridge Wells NHS hospitals (MTW).

In June and July 2020, during the first national lockdown, 248 family carers from across Kent, Surrey and Sussex (already recruited to the Time for Dementia programme) answered questionnaires which aimed to discover:

- the quality of life of people caring for someone with dementia
- the quality of life of people with dementia
- levels of social functioning of people with dementia, and
- the cognitive, functional ability of people with dementia.

The researchers also interviewed 12 carers to find out about their experience of day-to-day life during the pandemic.

This exercise has been repeated again, with 200 carers responding to the second questionnaire and a further 10 carers interviewed. The second round of data is currently being analysed and will be reported in the next few weeks.

The interim findings show that the impact of Covid-19 has been particularly impactful on carers living with someone with dementia.

Preliminary analysis of the questionnaire data showed:

- living with the person with dementia had a negative association with carer quality of life
- female carers reported lower quality of life of the person with dementia during lockdown compared to male carers
- female carers reported reduced social functioning in the person with dementia, compared to male carers

During the first round of Covid-19 restrictions, carers reported having a lack of freedom and a loss of control. Carers also stated that they were not able to have a break, and were unable to meet their own needs, as well as the needs of the person with dementia. Changes in emotional wellbeing, such as anger, sadness and exhaustion were also discussed.

Carers reported Covid-19 having an impact on the person with dementia, mainly a lack of understanding of the current pandemic or need for restrictions and a lack of stimulation. A reduction in dementia support services and a noticeable acceleration in cognitive decline of the person with dementia were noted by some. As reported earlier in the focus groups and when people shared individual stories.

“I’ve lost him during lockdown. We sit in the front room and although we are together, I am on my own. He doesn’t initiate any conversation.”

Carers also reported the difficulty of interacting with services if they aren’t fully involved in the care being provided.

“Better support from the hospital would have been important. Mum needed to be there to hear what the Doctor said on his rounds as Dad didn’t remember”

“I HATE phone consultations. My husband can’t do them and he just passes the phone back. The Haematology consultant and the GP both try to talk to him on the phone and every time we go through the same rigmarole of trying to explain that they need to talk to me instead as his carer”

7 Findings from public survey

The online public survey and the discussions with existing patient groups and forums focused on three broad questions:

1. What types of support do you think people with dementia and complex care needs and their families and carers would need, to help them live independently at home for as long as possible and avoid crises and unplanned stays in hospital?
2. What should good quality of care look like for people with dementia and complex needs, and their family and carers?
3. We have had suggested a number of guiding principles for improving services for people with dementia and complex care needs.

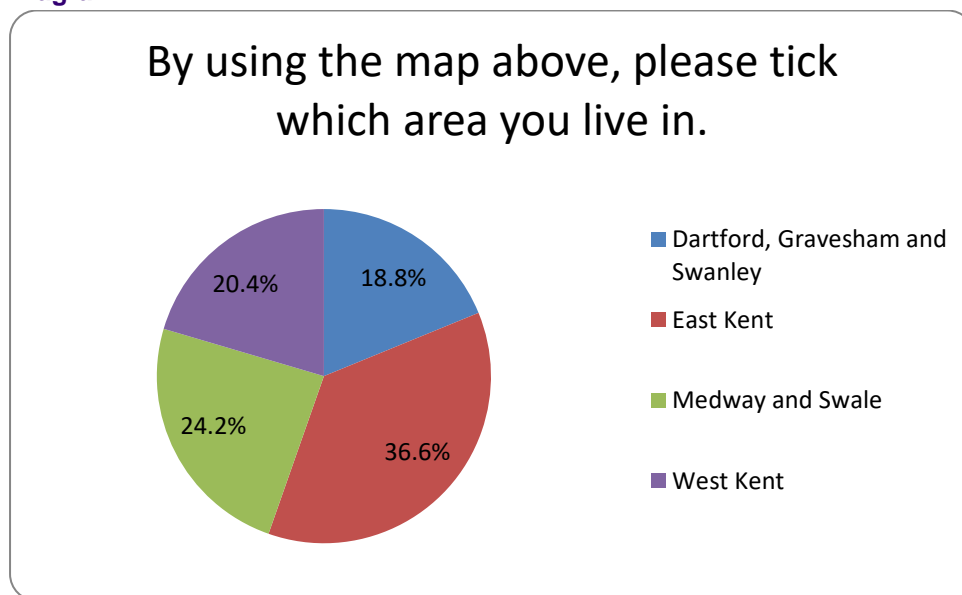
People were asked to place the principles listed below in order of importance.

- Treating the person with dignity and respect.
- Place the person at the centre of their care: understanding their history, lifestyle, culture and preferences, including their likes, dislikes, hobbies and interests.
- Family, carers and the person with dementia (where possible) should always be involved in developing a care plan based on person centred care. Their knowledge and understanding of the person is extremely valuable to make sure the care plan is right for them.
- Make the best use of the existing resources and expertise.
- Learn from best practice examples elsewhere.

We also asked: “What other guiding principles could we include to improve care for people with dementia and complex care needs?”

Diagram four below shows there was a good spread of responses from across Kent and Medway. In total, there were 190 responses.

Diagram 4



143 (75 per cent) of the respondents were female and table nine shows the age range of respondents.

Table 9

Answer Choice		Response Total
1	Under 18	0
2	18-24	2
3	25-34	5
4	35-44	18
5	45-54	22
6	55-64	45
7	65-74	68
8	75-84	18
9	85+	1

Table ten shows the ethnicity of the respondents who completed the monitoring question

Table 10

Answer Choice		Response Per Cent	Response Total
1	White British	93.7	164
2	White Irish	0.6	1
3	White Eastern European	1.1	2
5	Black African	1.7	3
7	Black British	0.6	1
9	British Asian	1.7	3
12	Mixed Race	0.6	1

The top three types of support people felt families and their loved ones need were:

- personal care in the home
- regular contact with a care navigator/support worker/case worker, and
- quality of care.

7.1. Personal care in the home

The importance of care being provided in the home was a prominent feature. The respondents highlighted day-to-day care being important, help with getting up and dressed and preparing of breakfast, lunch and dinner. Also people highlighted the benefits of socially interacting with the person living with dementia and encouraging them to take part in stimulating and physical activities.

7.2. Regular contact with a care navigator/support worker/case worker

Regular scheduled visits agreed with the person with dementia and their family where possible. In order to build a relationship and recognise the person’s individual needs it is preferable to assign the same carer.

7.3 Quality of care

The most mentioned factors when recommending good quality care were:

- a consistent service – same environment, same support worker etc.
- good communication and information
- integrated and seamless service

7.4 The principles guiding this work

The respondents were asked to rank in order of importance some guiding principles, which are shown in Table 11 below.

What should be the guiding principles for this work to improve dementia care for those with complex care needs

Table 11

Answer Choice		Overall Rank
1	Treating the person with dignity and respect	1
2	Make the best use of the existing resources and expertise	2
3	Learn from best practice examples elsewhere	3
4	Place the person at the centre of their care: understanding their history, lifestyle, culture and preferences, including their likes, dislikes, hobbies and interests.	4
5	Family, carers and the person with dementia (where possible) should always be involved in developing a care plan based on person centred care. Their knowledge and understanding of the person is extremely valuable to make sure the care plan is right for them.	5

It can be seen from the table that treating the person with dignity and respect is most important, followed by making the best use of existing resources and knowledge and learning from best practice elsewhere.

There were other suggestions of guiding principles to be included: consistent service and care, that services are integrated and seamless, and good communication and information.

8 Feedback from existing local area patient groups and forums

There are eight local area groups across Kent and Medway facilitated by the KMCCG; and we also spoke to three county wide forums supported by Engage Kent. These are made up largely from patient participation group (PPG) members, Healthwatch volunteers, residents associations and local voluntary and community organisations.

Table 12 below shows the number of people who attended the meetings:

Table 12

Local Area Group	Number of Attendees
Ashford	9
Canterbury and Coastal	11
Dartford, Gravesham and Swanley	6
Medway	11
South Kent Coast	23
Swale	5
Thanet	10
West Kent	24
County Mental Health Action Group (MHAG)	8
Disability Forum	9
Older People's Forums, including over 50s forums	5

The groups were asked the same questions as the public survey (Appendix E) which focused on: what type of support people living with dementia and complex care needs want, what good quality care looks and feels like and commenting on and contributing to the guiding principles for this work to improve dementia care.

Across all the groups there were five themes that were discussed the most, which were:

- support for carers
- integration of services
- importance of care plans
- respite care
- importance and need for staff training

8.1 Support for carers

The dominating theme across all groups was the importance of support for carers, who were caring for their loved ones at home.

People highlighted that the amount of information given to families at the point of diagnosis, varies by locality. Some families are given too much written information to take away at diagnosis and were unable to take it all in, whereas others find

'they aren't given enough help with what happens after diagnosis and where they can go for support.'

It was suggested that it would be helpful to have a care navigator, or a support /link worker to provide families with ongoing support with:

- identifying local community support groups
- helping them to understand the diagnosis and what it means
- supporting them to claim for financial help and their entitlements, and

- how to seek other interventions as the disease progresses and circumstances change.

Many people suggested more awareness raising of dementia, the early signs and symptoms and the services to visit, in order to start the process of diagnosis early.

8.2 Integration of services

All groups discussed services which currently support people living with dementia. It was made clear that these services do not always work together and families have to tell their story more than once. It should be noted, dementia services are not the only service this affects but it may cause particular difficulties for people living with dementia. What sometimes happens is families are missed and “slip through the net” or families end up having to chase services for various reasons.

“I can spend a whole day just chasing services about my mums care”

Many felt services, particularly health and social care, need to work better together, they should take a ‘person centred approach’ and be consistent.

8.3 Care plans

There was mixed views about care plans, although one group agreed the importance of a care plan; they were clear it would only work if the person living with dementia, their family and the services involved, all had sight of the care plan and owned it.

“The family and the carers should be in the Care Plan and involved from the onset”

8.4 Respite care

All groups raised the issue of respite care and the importance of carers having a break which will benefit them mentally and physically.

“Respite needs to be factored into the community care so that carers do not end up burnt out and the family can continue fully supported.”

“Carers need respite, a decent amount of respite and please do not forget young carers. There’s a time when the person with dementia needs to go to a residential setting to give the carer 24/48hrs break, and also times that someone comes into their own home so the carer can go for a walk knowing their loved ones are being taken care of.”

The importance of overnight respite, whether provided in a residential/care home or in the person’s own home.

“Night cover is needed. Whatever care goes on during the day, people at night can become frightened. The night time is a strong issue which can result in people having to go into a residential/care home setting.”

“Night cover/night support to help the person even if they are living with the family, so the carers can get a rest.”

8.5 Staff training

There were discussions about staff training and there was a feeling this needs to be more frequent, not just for care homes but also for hospital staff and private care companies.

“Training isn’t mentioned and staff in care homes need extra training and to increase their understanding. This would need to be for both formal and informal carers.”

“It is essential that community carers or domiciliary care services have mandatory training on dementia.”

9 Other learning points for the future

There are several specific suggestions within the feedback from the focus groups, which commissioners should take into account and consider as suggestions for improving dementia care. They build on the feedback and themes within the report.

Also, there are a couple of points which were mentioned which we believe should be considered by commissioners and their partner organisations when developing proposals for improving services/care.

1. There was a strong suggestion of services needing to be more integrated and working together better. This was in particular reference to the NHS and social care working together and the individual’s care plans being person-centred and available to all services.
2. There were comments made about the behaviour of a loved one living with dementia as they are very good at showing others that everything is fine and they are managing or coping. A particular reference was made to social services when they visited and carried out an assessment.

“My father in law managed to deceive Social Services by coming across as being well and his dementia wasn’t as progressed as it was. He was in denial of the diagnosis.”

3. People reiterated that services need to take into account the carer and or families experience as well as the person living with dementia. In Canada there is a culture of families and carers being considered care partners.

“Principle 3 is very important – take into consideration the individual’s needs, but stay connected to family and carers.”

4. The importance of housing associations was raised. Many people living with dementia live in sheltered housing and the housing organisations can play a vital role looking out for their tenants.

“Make sure to include housing – social housing and the support it offers is an important part of the picture which is too often over looked. Sheltered housing could be a key partner.”

5. Families of loved ones living with dementia shared their fears over finances and how they will be able to live once their loved one goes into a care home; or if they need to give up work/retire permanently. It was highlighted that there is a need for funding streams for families’ needs to be coordinated and readily available.

“Continuing Healthcare, personal budgets and direct payments need to run smoothly to give families control and support in their own homes.”

6. The importance of care homes and both the continuing health care (CHC) assessment process and the process by which families find a suitable care home was raised. It needs to be easier to find homes which can happily care for and manage people with dementia and complex care needs which may include challenging behaviour. This was specifically raised by the families who had used the Frank Lloyd Unit. Sometimes it took several changes to locate the right place and people were extremely pleased when they found somewhere which worked well for their loved one. It was felt that more support could be given to assist in the challenge.

Jeff had Alzheimers, Dilys had Parkinsons and later dementia: this is an extract from their story:

“they moved into sheltered accommodation near one of my brothers where house prices were lower, and I would also relocate to the area so there was a good support network. My mother was concerned about leaving all the support services she had in place – and she was right – there seemed little joined up thinking and we felt we were starting again with everything.

My parents paid for carers to visit 4 times a day and I went round at least once a day. My brother and his wife also supported weekly. Other family visited when they were able. Her GP suggested that the stress on her was making her condition worse and that we should try a fortnight’s holiday for Jeff, in a care home. He settled in really well, but Dilys found she couldn’t cope without him. I found the level of care too great and so she went into a home for respite. However, the home could not manage and she ended up in hospital. She was released to an assessment placement but ended back up in hospital. Her assessment showed that she needed nursing care rather than a care home, and once we found a suitable home, she lived there happily for the last 6 years of her life.”

10 Conclusion

This research has clearly shown that there is a need for more support for families and carers who are supporting a loved one who has dementia and potentially complex needs. The need for this has been made all the more poignant by the pandemic and the pressure of being locked down with many support and public services having to work remotely.

Early and universal assistance to people so they can find suitable help and support would be welcomed - single points of access, care coordinators, directories of services and route maps of what to expect – with a human guide, were all suggested.

Services are well used and many were praised, but in terms of improvement people felt there should be more effort to make them accessible, consistent, integrated, person centred and always there when both the person living with dementia and/or their carer needs them.

Staff supporting people living with dementia and their families do use care plans, and receive training – but others felt it wasn't necessarily consistent enough or evident in how people worked.

Staff feel they know where to signpost people to for support and know which services to call upon when a person shows challenging behaviours, yet they also recognised that carers and families felt unsupported and the majority 98 per cent of our respondents agreed a crisis service was needed not just in working hours but 24 hours, seven days a week.

And that, most of all, no-one should feel they are on their own or unsupported.

“It feels like us against the world at times.”

Appendix A

Improving care for people living with dementia and complex care needs - Staff Survey

1. Introduction

NHS organisations across Kent and Medway are thinking about how to improve care for people with severe dementia and complex care needs. In 2020, there are estimated to be 27,000 people living with dementia in Kent and Medway. This number is expected to rise to 38,000 over the next 10 years. Roughly two thirds of people who have dementia live in their own homes and one third live in care homes. Dementia can be mild, moderate, or severe.

- 15,000 or 55.4 per cent of people will have mild dementia
- 8,750 or 32.1 per cent of people will have moderate dementia
- 3,500 or 12.5 per cent of people will have severe dementia.

Research shows that it is better for people who have dementia and complex care needs to continue to live in their own homes, for as long as possible: meaning that we need services to continue to support them and their families and carers where they usually live. When people with dementia cannot stay in their own home they usually move to a care home to receive the care they need.

Sometimes people with dementia can exhibit behaviours which can challenge both their families, and care staff. Over time they may experience difficulties with mobility or deterioration in their health which means they are better looked after somewhere else for a short period. Perhaps they need a medication review, or specialist care, particularly if they are exhibiting difficult or challenging behaviours; they may even be admitted temporarily to a hospital inpatient bed, or a specialist care facility.

We need to make sure that there is the right level support in all parts of the health and care system, to respond to changes in people's health particularly when the symptoms are severe, and prevent, or manage, any crises.

We also need to recognise and support families and carers and understand that their physical and mental health can be affected, especially when the person whom they care for has complex needs.

We need to hear from care home staff, domiciliary carers, NHS and social care staff and those voluntary organisations who support people living with dementia and their families to cope with changes in their health. We want to understand how well our care system is working, whether there are any gaps, such as out of hours or crisis care, and if there are any innovations and assistance you would want to improve the running of your service and its resilience. We are particularly keen to hear from you at this difficult time, when Covid-19 is challenging many aspects of our health and care system and revealing increased strains on those coping with a debilitating condition like dementia.

Please take 15 minutes to complete this short survey by Friday 15 January 2021.

Kent and Medway



1. By using the map above, please tell us which area you cover. Please tick all that apply.

Dartford, Gravesham and Swanley

East Kent

Medway and Swale

West Kent

2. Please tick the organisation you work for:

Acute Trust

Community Trust/Community Service

Domiciliary Care Services

Nursing Home

Residential Care Home

Secondary Mental Health Services

Social Care Service

Voluntary and Community Organisation

Other (please specify):

Personalised Care

3. If you have an integrated care plan for each of your patients/ residents, does this help you to identify and manage changes in people's health?

Yes

No

I don't know

4. Does this plan contain information about the person which helps to identify triggers for behaviours that can challenge services and how to manage it?

Yes, a lot of detailed information

Yes, some information

No

I don't know

5. From the list of potential benefits associated from personalised care plans below, please put them in order of importance, where 1 is the most important to 5 being the least important.

- Patient/resident's dignity is respected
- Everyone involved in their care has the same information
- We know what the patient responds best to and any triggers which confuse or anger them.
- We know which medications are being used and current symptoms
- We know of any choices or directions about healthcare given by the patient, their carer or family

6. Do you think the family/carers of the people you look after, receive the help they need to look after themselves, and their own physical and mental health?

Yes

No

I don't know

7. Are you aware of local organisations which offer families help and advice who you can refer them to?

Yes

No

I don't know

Comments:

Changing levels of need

8. If a patient/resident's health gets worse, or their behaviours become more challenging where do you go for support during usual working hours?

GP Practice

Urgent Treatment Centre

Hospital Emergency Department

NHS 111

Specialist Mental Health Service Team

Community Geriatrician/Nursing Service

Ambulance Service

Other (please specify):

9. Which service do you go to for support outside of working hours, in the evenings, and at weekends?

GP Practice

Urgent Treatment Centre

Hospital Emergency Department

NHS 111

Specialist Mental Health Service Team

Community Geriatrician/Nursing Service

Ambulance Service

Other (please specify):

10. If there have been occasions where you have been unable to access crisis/urgent support, what has usually happened?

The patient/resident has been admitted to hospital

The patient/resident has been admitted to a mental health hospital

The patient/resident has been admitted to a Care Home

The resident has been given one to one support in the place where they usually live

Other (please specify):

11. Do you think there is a need for a crisis/urgent care service to support people with dementia, when their health deteriorates, but you wish to keep them at home?

Yes

No

I don't know

12. Please indicate below the working hours that you think would be most appropriate for a community-based crisis service. Please rank in the order you would prefer.

Monday to Friday 9am-5pm

Monday to Sunday 9am-5pm

Monday to Friday 8am-8pm and Saturday and Sunday 9am-5pm

Monday to Sunday 9am-8pm

Monday to Sunday 24/7

13. What type of support/treatment should this service provide? Please tick one or more of the statements below

Taking blood to support diagnosis

Provide IV/subcutaneous (under the skin) fluid

Provide IV antibiotics

Medication review/prescribing

Support to manage challenging behaviours

Other (please specify):

Staff training and specialist support

14. Have you received specific and regular training on delivering care for people with dementia?

Yes, we are specially trained in dementia care for our patients

Yes, we receive training annually

Yes, occasionally

No, I was trained before I arrived

No, there is no time for extra training

No, there are not enough staff to release people for training

No, we are monitored and supported whilst providing care.

Other (please specify):

15. Do you receive regular training and support on how to manage behaviours that can challenge services?

Yes

No

I don't know

16. Do you receive any external support to help keep your patients well and active? Please tick any professionals or groups that support you.

GPs

Geriatricians

Specialist Mental Health Nurses

Admiral Nurses

Occupational Therapy

District Nurses

Physiotherapy

Voluntary organisations offering patients advocacy or support activities such as Dementia UK, Alzheimers Society, Age UK

Social Care - advice on support, benefits

Other (please specify):

Improving health and care for people with dementia

Improving health and care for people with severe dementia and complex care needs is very challenging, never more so than now.

17. From your perspective, what improvements could be made for caring and supporting someone living with dementia?

18. From your perspective what is the greatest challenge about caring and supporting someone living with dementia usually, when there is not a pandemic?

19. From your perspective what is the greatest challenge about caring and supporting someone during a pandemic and Covid-19 measures and protocols are in place?

20. Are there any further comments you would like to make?

About You

Please tell us a little about yourself. All information we receive will be anonymised and it will help us to monitor who has responded.

21. Please tell us your gender

Male

Female

Prefer not to say

22. Please tick your age group

Under 18, 18-24 25-34 35-44 45-54 55-64 65-74 75-84 85+

23. Please tick your ethnicity or ethnic group

White British White Irish White Eastern European

Gypsy or Traveller

Black African Black Caribbean Black British

Asian British Asian Nepalese Bangladeshi

Mixed Race

Arab

Somali

Chinese

Appendix B

Improving care for people living with dementia and complex care needs - Public Survey

Introduction

NHS organisations across Kent and Medway are thinking about how to improve care for people with dementia and complex care needs. In 2020, there are estimated to be 27,000 people living with dementia in Kent and Medway. This number is expected to rise to 38,000 over the next 10 years. Two thirds of people who have dementia live in their own homes and one third live in care homes. Dementia can be mild, moderate, or severe. Approximately:

- 15,000 or 55.4 per cent of these people have mild dementia.
- 8,750 or 32.1 per cent of these people have moderate dementia.
- 3,500 or 12.5 per cent of these people have severe dementia.

Evidence shows it is better for people with dementia to continue to live in their own homes for as long as possible. Services are needed which support them where they live, so any changes or fluctuations in their health can be managed and any crisis prevented or dealt with appropriately. We recognise the impact on families and carers and want to make sure the care and support we provide for people living with dementia takes account of their needs too.

Kent and Medway Clinical Commissioning Group is working with its partners, and people living with dementia and their carers to improve dementia care. We are at an early stage of developing proposals for an intensive community service for people with dementia which will support people in the own homes and care homes (both residential and nursing) at times of crisis and urgent need, with the aim of avoiding hospital admission where possible. There will also be a need for specialist support for people with dementia and beds for those with the most challenging behaviour and complex needs until their health improves.

We are gathering the experience and views of people living with dementia and their carers, and of staff from health and social care to feed into this process at an early stage.

We would also like to hear your views, as a member of the public.

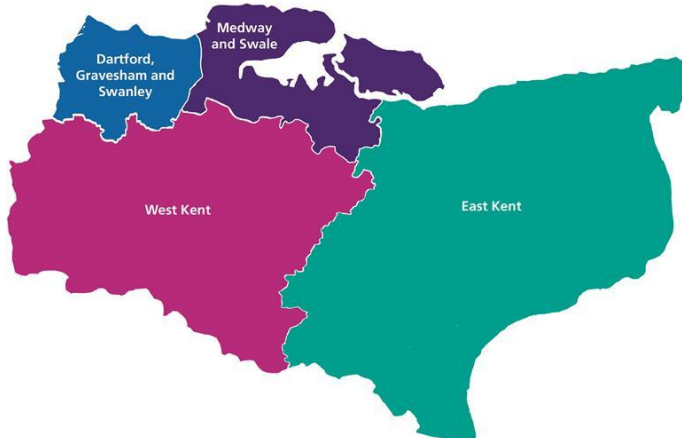
We are interested in your views about the principles which should improve the quality of care provided for people living with dementia. What you would expect and want for yourself or your loved ones if you were to develop dementia?

If you want to respond as an interested member of the public, please complete our survey by Friday 15 January 2021.

We also want to hear from people with lived experience of dementia care and their families/carers. If you know someone who might have a story to share, please ask them to contact us at kmccg.engage@nhs.net or call Katie Blissett on 07545934705. We're happy to let them choose how best we capture their personal story.

Kent and Medway

1. By using the map above, please tick which area you live in.



Dartford, Gravesham and Swanley

East Kent

Medway and Swale

West Kent

2. What types of support do you think people with dementia and complex care needs and their families and carers would need, to help them live independently at home for as long as possible and avoid crises and unplanned stays in hospital?

3. What should good quality of care look like for people with dementia and complex needs, and their family and carers?

4. We have had suggested a number of guiding principles for improving services for people with dementia and complex care needs. Please place the sentences below in order of importance to you.

- Treating the person with dignity and respect
- Place the person at the centre of their care: understanding their history, lifestyle, culture and preferences, including their likes, dislikes, hobbies and interests.
- Family, carers and the person with dementia (where possible) should always be involved in developing a care plan based on person centred care. Their knowledge and understanding of the person is extremely valuable to make sure the care plan is right for them.
- Make the best use of the existing resources and expertise
- Learn from best practice examples elsewhere

5. What other guiding principles could we include to improve care for people with dementia and complex care needs? Please list any suggestions below

About You

Please tell us a little about yourself. All results will be anonymised; this information will help us to monitor who has responded.

6. Please tell us your gender

Male Female Prefer not to say

7. Please tick your age group

Under 18 18-24 25-34 35-44 45-54 55-64 65-74 75-84 85+

8. Are you

Heterosexual (Straight) Gay or Lesbian Bisexual Prefer not to say

Other (please specify):

9. Do you have a disability?

Yes

No

Prefer not to say

10. Do you care for someone else?

Yes, child/children

Yes, an adult/s

No, I don't care for someone else

11. Please tick your ethnicity or ethnic group.

White British White Irish White Eastern European

Gypsy or Traveller

Black African Black Caribbean Black British

Asian British Asian Nepalese Bangladeshi

Mixed Race

Arab

Somali

Chinese

Appendix C

Improving care for people living with dementia and complex care needs

The NHS in Kent and Medway want to design a service which supports people living with dementia to stay where they live, so any changes or fluctuations in their health can be managed and any crisis prevented or dealt with appropriately. We also need to make sure we provide care and support to meet the physical and mental health needs of families and carers.

NHS Kent and Medway Clinical Commissioning Group (CCG) is working with partners including Kent and Medway NHS and Social Care Partnership Trust, local hospitals, local authorities, care homes, voluntary and community sector and others to develop this new model of care. There is a clinical reference group leading the work and exploring best practice models, and gathering evidence on current services, and people's needs.

This autumn and winter we are seeking views from as many people as possible to help us design a new service, which will provide support to people with dementia and their carers, at times of crisis and avoid a hospital admission where possible.

We are proposing a dementia support service to supplement the community services already provided in Kent and Medway which will provide a crisis response, to people living in their own homes and in care homes. The aim will be to prevent admission to hospital when possible, as this can produce poor outcomes for people with dementia.

We need your help this autumn, as we want to hear from people with lived experience of dementia and complex care needs.

Stories told by individuals from their perspective, can provide us with an opportunity to understand your experience of the care you or your loved one have received; helping us to learn from the good, and the bad and look at what can be done to improve people's experience in the future.

For this journal, we would like to hear about how you cope in a crisis, the types of service you rely on, and any gaps you see in care and support services and any improvements you would want?

About You

Please tick which area of Kent you live: East Kent Dartford, Gravesham and Swanley Medway and Swale West Kent

Please tell us your gender: Male Female Prefer not to say

Please tick your age group: Under 18 18-24 25-34 35-44 45-54 55-64 65-74 75-84
85+

Please tell us your ethnicity or ethnic group:

Are you: caring for a loved one with dementia living with dementia

How long the person has been living with dementia/caring? Years Months

Please tell us in the box below, a little bit about the person who has dementia

Their name, age and a little bit about them: where do you live, what did they do, what do they enjoy doing, have they any interests or achievements they are proud of?

age 65

Please tell us about what it's like for you day-to-day living with dementia or caring for someone with dementia

- Living every day and how you cope
- the support services you use
- any gaps or support you need which aren't there?
- Is there any one/organisation who has been particularly helpful and ideas for how things could be improved?

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Thank you for taking the time to share your story with us. We hope that by learning from your experiences we can help to improve the services on offer to support people living with dementia, and help their families too. If you would like to record your story on film, or share more details, please leave your name and contact details:

Name:

Contact details (Phone/Email):

Appendix D

Improving care for people living with dementia and complex care needs - Public Survey

Community Focus Group Briefing, Questions and Answer Template, November 2020

What are we trying to do

NHS organisations across Kent and Medway are thinking about how to improve care for people with dementia and complex care needs. In 2020, there are estimated to be 27,000 people living with dementia in Kent and Medway. This number is expected to rise to 38,000 by 2030. Of these approximately 15,000 people have mild dementia, 8,750 have moderate dementia and 3,500 have severe dementia. Roughly two thirds of people with dementia live in their own homes and one third live in care homes.

Evidence shows it is better for people with dementia to continue to live in their own homes for as long as possible. Services are needed which support them where they live, so any changes or fluctuations in their health can be managed and any crisis prevented or dealt with appropriately. We recognise the impact on families and carers and want to make sure the care and support we provide for people living with dementia takes account of their needs too.

Kent and Medway Clinical Commissioning Group is working with its partners, and people living with dementia and their carers to improve dementia care. We are at an early stage of developing proposals for an intensive community service for people with dementia which will support people in the own homes and care homes (both residential and nursing) at times of crisis and urgent need, with the aim of avoiding hospital admission where possible. There will also be a need for specialist support for people with dementia and beds for those with the most challenging behaviour and complex needs until their health improves.

We are gathering the experience and views of people living with dementia and their carers, and of staff from health and social care to feed into this process at an early stage. We also want to hear from people who may not have direct experience but who can tell us about what they would expect.

What we want to find out

The CCG and its partners in the NHS want to know about people's current experiences of dementia care. We also want to find out about what needs to be improved and also what you think about what matters most – the principles for improvement. What you would expect and want for yourself or your loved ones if you were to develop dementia.

Who we want to hear from

We are interested in hearing from anyone with an experience of dementia support or of caring with someone with dementia. We are interested in hearing from families about what they would expect and want – even if their loved ones do not have complex needs. We know community groups in Medway and Swale are particularly good at reaching families who would not normally speak to the NHS or to public services – people who may be living in difficult circumstances or who have other barriers to speaking out.

The CCG is also speaking to care home staff and to those who work in frontline services.

What we will do with results

The facilitators will create a record of each discussion using a discussion pro-forma. All information will be anonymous –no names will be supplied. This will be collated by MVA and passed to NHS Kent and Medway Clinical Commissioning Group.

FOCUS GROUP DISCUSSION GUIDE

Welcome and thank you for volunteering to take part in this focus group. You have been asked to participate as your point of view is important. I realise you are busy and I appreciate your time.

1.	Introduction: Introduce self and any co-facilitators – including from the CCG/MVA. Tell the group what your role is and the roles of the other facilitator. NHS organisations across Kent and Medway are thinking about how to improve care for people with dementia and complex care needs. Evidence shows it is better for people with dementia to continue to live in their own homes for as long as possible. Services are needed which support them where they live. Kent and Medway Clinical Commissioning Group is working with its partners, and people living with dementia and their carers. We want to build an intensive community service to support people in the own homes and in care homes (both residential and nursing) at times of crisis and urgent need. The aim is to avoid hospital admission where possible. The project is at an early stage – there are no right or wrong answers – we want to know what matters to families, to carers and to professionals in the community.
1.1.	Consent:

	<ul style="list-style-type: none"> - To facilitate our recollection of this session I/we take notes during the session on what is being said – is that okay with everyone? Also [If recording the session] may I record the discussion? (if yes, switch on the recorder) - Everyone should now have seen a copy of the Participant Information and Consent Sheet? (Has everyone read and understood the information given in this document (check that everyone has and respond to any questions)? By remaining and participating in this session, I am now assuming that you are given consent to take part in this research project.
1.2.	<p>Anonymity:</p> <ul style="list-style-type: none"> - Despite notes being taken, I would like to assure you that the discussion will be anonymous. You should try to answer and comment as accurately and truthfully as possible. - I and the other focus group participants would appreciate it if you would refrain from discussing the comments of other group members outside the focus group.
1.3.	<p>Ground rules:</p> <p>Ask the participants to agree ground rules for the session – suggested rules might include:</p> <ul style="list-style-type: none"> - Only one person speaks at a time. There may be a temptation to jump in when someone is talking but please wait until they have finished. - There are no right or wrong answers - You do not have to speak in any particular order - When you do have something to say, please do so. There are many of you in the group and it is important that I obtain the views of each of you - You do not have to agree with the views of other people in the group <p>Does anyone have any questions? (answers). OK, let's begin</p>
1.4.	<p>Warm up:</p> <p>First, I'd like everyone to introduce themselves. Can you tell us your name? (if appropriate your role/ what you do)</p>
2.	<p>The services used by you/ your families/ your clients</p> <p>Find out how many people in the group are family carers or have direct experiences of dementia – in what way Can you tell us a bit about which services you use to support care for people with dementia, or how you get help or support? (if from community organisations – which services in the community do you offer? Tell us a bit about what you do to support people? How do the families you work with get help and support for dementia care?)</p>
2.1	<p>What works and does not work currently for families and carers?</p> <p>Please tell me what is good about the services which currently exist to help people? What do families use which work?</p> <p>What works less well? Where are the gaps?</p>
3.	<p>What support do families need to live independently and avoid crises</p> <p>When there is a crisis or your family or the families you work with have a change in circumstances, what happens and what support is there?</p> <p>What types of support do you think people with dementia and complex care needs and their families and carers need to help them live independently at home for as long as possible and avoid crises and unplanned stays in hospital?</p>
4.	<p>The principles for improved services.</p> <p>Families and paid and unpaid carers have told the CCG about what matters to them. We have used these discussions to develop some principles for care for people with dementia and complex care going forward and we want to know what you think about these principles.</p> <p>Do you think any or all of these are all important, or are some more important than others? Are there any principles which should be added?</p> <p>Read out or show the principles on a slide to the group – ask them to add to these if they feel anything is missing, whether any are more important than others and why.</p> <p><i>“There are a range of services that support me with any aspect of daily living and enable me to stay at home and in my community, enjoying the best quality of life for as long as possible.”</i></p> <ul style="list-style-type: none"> • Treating the person with dignity and respect. • Place the person at the centre of their care: understanding their history, lifestyle, culture and preferences, including their likes, dislikes, hobbies and interests. • Family, carers and the person with dementia (where possible) should always be involved in developing a care plan based on person-centred care. Their knowledge and understanding of the person is extremely valuable to make sure the care plan is right for them. • Make the best use of existing resources and expertise. • Learn from best practice examples elsewhere

5	Anything else? Is there anything else you wish to tell us about what might help people with dementia stay in their home?
6.	<p>Close the focus group session</p> <ul style="list-style-type: none"> - Thank you for participating. This has been a very successful discussion and your opinions are valuable to NHS Kent and Medway Clinical Commissioning Group - I will send a report summarising today's discussions to Medway Voluntary Action. They will collate the information in this report with other focus group reports from Medway – and all of this data will be passed to the CCG - The CCG and its partners will use the information to plan improvements to community based services. - I would like to remind you that any comments featuring in this report will be anonymous. - Thank you once again for your time and this focus group session is now closed.

FOCUS GROUP REPORT TEMPLATE

Please ensure this form is completed and returned to MVA's Involving Medway programme team no later than Friday 18th December.

On completion of the group, the outcomes need to be reported and submitted for consideration in the formal consultation. Remember, the simple sense tests for your reported outcomes are:

- Could you give this to the average person to read?
- Would they understand it?

Introduction	
1. Record of group	
Facilitator Details	
Note Taker Details	
Date group session held	
How the event was held – zoom?	
Number of participants	
Anonymised Demographics (e.g. 4 male, 4 female, aged xx to zz, all of whom were service users)	
General Questions Summary. Please ensure you include: <ul style="list-style-type: none"> • participant quotations • details derived from probing questions • general visual and audio observations (e.g. body language, strong consensus, questions receiving strong responses, raised voice)) 	
2. Services used/ offered	
List the situation of the participants and which services are used by families locally	
3. Living independently, avoiding crises	
List support needed by local families to live as long as possible at home	
4. Principles	
Which are the most important principles? Anything else to add to them	
5. Anything else	
What else matters to people with dementia and their carers?	
Further comments/ views	
Report Completed by	
Date completed	

Once completed, please return this form to MVA's Involving Medway programme team by 18th December:

involvingmedway@mva.org.uk

Appendix E

Questions



1. What types of support do you think people with dementia and complex care needs and their families and carers would need to help them live independently at home for as long as possible and avoid crises and unplanned stays in hospital?

2. What should good quality of care look like for people with dementia and complex needs, and their family and carers?

Questions



3. We have listed a number of guiding principles for our work suggested by patients and the public. Do you think any or all of these are all important or are some more important than others? Are there any principles which should be added?

"There are a range of services that support me with any aspect of daily living and enable me to stay at home and in my community, enjoying the best quality of life for as long as possible."

- Treating the person with dignity and respect.
- Place the person at the centre of their care: understanding their history, lifestyle, culture and preferences, including their likes, dislikes, hobbies and interests.
- Family, carers and the person with dementia (where possible) should always be involved in developing a care plan based on person-centred care. Their knowledge and understanding of the person is extremely valuable to make sure the care plan is right for them.
- Make the best use of existing resources and expertise.
- Learn from best practice examples elsewhere

Item 6: Urgent Care Review Programme - Swale

By: Kay Goldsmith, Scrutiny Research Officer

To: Health Overview and Scrutiny Committee, 4 March 2021

Subject: Urgent Care Review Programme - Swale

Summary: This report provides the background to the agenda item.

The Committee has yet to determine if the proposals constitute a substantial variation of service.

There will be a verbal update from the Kent and Medway CCG at the meeting.

1) Introduction

- a) The Local Urgent Care Programme review was first presented to HOSC in 2014. It was in response to an NHS England requirement for all areas to have an Urgent Treatment Centre (UTC) to try and reduce the pressure on A&E departments.
- b) The review refers to face-to-face urgent care services, as opposed to telephony services which have been procured separately. Urgent care relates to injuries or illnesses that are not life-threatening but that require urgent clinical assessment or treatment on the same day.¹
- c) In September 2019, provision for urgent care to Swale residents included:²
 - i) A GP out of hours service with bases at Sheppey Community Hospital and Sittingbourne Memorial Hospital as well as a home-visiting service.
 - ii) A nurse-led minor injuries unit at Sheppey Community Hospital and Sittingbourne Memorial Hospital.
 - iii) A GP operated walk-in-centre from Sheppey Community Hospital, Sittingbourne Memorial Hospital and a mobile unit.
 - iv) A 24/7 GP led urgent treatment centre at Medway Maritime Hospital.

2) Previous visits to HOSC

- a) HOSC has received updates about the urgent care review programme since 2014.
- b) Swale CCG had initially considered a “minimal change” clinical model, but this was discontinued in November 2018 after it was deemed unaffordable. It was decided a full-service specification/ clinical model review was necessary, which would involve working alongside Medway CCG whose facilities were used by Swale residents.

¹ Kent County Council (2019) Health Overview and Scrutiny Committee, Swale CCG Urgent Care update (19/09/19)

² ibid

Item 6: Urgent Care Review Programme - Swale

- c) At its 19 September 2019 meeting, HOSC received an update from Swale CCG and was notified the clinical model options had not yet been identified. The CCG was undertaking a detailed clinical review of data from their urgent and emergency care services and findings were expected in September/October 2019. Quantitative and qualitative data analysis that had been carried out to date was presented to the Committee.
- d) Swale CCG informed the Committee that the NHS Long Term Plan required that their urgent care proposals be in place by autumn 2020.
- e) Following the above discussion, the Committee agreed:

RESOLVED that the Committee note the report and that the NHS be invited to attend a future meeting when there was more information available on the new model of care being developed, at which time the Committee would be able to determine whether it would be deemed a substantial variation of service.
- f) The CCG has been requested to provide a verbal update at this HOSC meeting.

3) Recommendation

RECOMMENDED that the update be noted and the Kent and Medway CCG return to update the Committee at an appropriate time.

Background Documents

Kent County Council (2014) 'Health Overview and Scrutiny Committee (10/10/2014)', <https://democracy.kent.gov.uk/ieListDocuments.aspx?CId=112&MId=5400&Ver=4>

Kent County Council (2016) 'Health Overview and Scrutiny Committee (26/01/2016)', <https://democracy.kent.gov.uk/ieListDocuments.aspx?CId=112&MId=6256&Ver=4>

Kent County Council (2017) 'Health Overview and Scrutiny Committee (27/01/2017)', <https://democracy.kent.gov.uk/ieListDocuments.aspx?CId=112&MId=7507&Ver=4>

Kent County Council (2017) 'Health Overview and Scrutiny Committee (14/07/2017)', <https://democracy.kent.gov.uk/ieListDocuments.aspx?CId=112&MId=7530&Ver=4>

Kent County Council (2018) 'Health Overview and Scrutiny Committee (23/11/2018)', <https://democracy.kent.gov.uk/ieListDocuments.aspx?CId=112&MId=7923&Ver=4>

Kent County Council (2019) 'Health Overview and Scrutiny Committee (25/01/2019)', <https://democracy.kent.gov.uk/ieListDocuments.aspx?CId=112&MId=7924&Ver=4>

Item 6: Urgent Care Review Programme - Swale

Kent County Council (2019) 'Health Overview and Scrutiny Committee (23/07/2019)
<https://democracy.kent.gov.uk/ieListDocuments.aspx?CId=112&MId=8282&Ver=4>

Kent County Council (2019) 'Health Overview and Scrutiny Committee (19/09/2019)
<https://democracy.kent.gov.uk/ieListDocuments.aspx?CId=112&MId=8283&Ver=4>

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Item 7: CQC inspection update for Medway Foundation Trust

By: Kay Goldsmith, Scrutiny Research Officer

To: Health Overview and Scrutiny Committee, 4 March 2021

Subject: CQC inspection update for Medway Foundation Trust (written update)

Summary: This report provides the Committee with background to the agenda item.

There will be a supplementary paper from Medway Foundation Trust once the Care Quality Commission publishes their report on 25 February 2021.

This is a written briefing only and no guests will be present to speak.

1) Introduction

- a) The Care Quality Commission carried out an unannounced inspection of Medway Maritime Hospital's emergency care pathway and emergency department on 14 December 2020. Subsequently the regulator has issued a Section 31 notice (possible urgent enforcement actions) and a Section 29A (letter of intent).
- b) The enforcement notices were highlighted in the agenda papers for Medway Foundation Trust's Board of Directors meeting on 4 February 2021¹.
- c) The Care Quality Commission are publishing the report of their findings, including where improvements are required, on Thursday 25 February. Therefore, a supplementary paper will be published to this agenda once that has happened.

What is a Section 29A warning notice?²

- d) The CQC can serve a warning notice under section 29A of the Health and Social Care Act 2008 when it identifies concerns across either the whole or part of an NHS Trust or NHS Foundation Trust and it determines there is a need for significant improvements in the quality of healthcare.

What is a Section 31 notice?³

- e) If the CQC has reasonable cause to believe that unless it acts a person may or will be exposed to harm, they may give notice in writing under Section 31 of the Health and Social Care Act 2008 to the provider.

¹ Medway NHS Foundation Trust, <https://www.medway.nhs.uk/downloads/publications/board-papers/PAPERS-Trust-Board-in-Public-04.02.21.pdf>

² Care Quality Commission, Section 29A warning notices for NHS trusts and NHS foundation trusts, <https://www.cqc.org.uk/sites/default/files/20170210-guidance-on-section-29a-warning-notices-final.pdf>

³ The Health and Social Care Act 2008, section 31.

Item 7: CQC inspection update for Medway Foundation Trust

- f) The Provider has been invited to update the Committee on its action plan following the issuing of the notices.

2) Recommendation

RECOMMENDED that the Committee consider and note the report.

Background Documents

None

Contact Details

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Item 8: Work Programme 2021

By: Kay Goldsmith, Scrutiny Research Officer
To: Health Overview and Scrutiny Committee, 4 March 2021
Subject: Work Programme 2021

Summary: This report gives details of the proposed work programme for the Health Overview and Scrutiny Committee (HOSC).

1. Introduction

- a) The proposed Work Programme has been compiled from actions arising from previous meetings and from topics identified by Committee Members and the NHS.
- b) The HOSC is responsible for setting its own work programme, giving due regard to the requests of commissioners and providers of health services to bring an item to the HOSC's attention, as well as taking into account the referral of issues by Healthwatch and other third parties.
- c) The HOSC will not consider individual complaints relating to health services. All individual complaints about a service provided by the NHS should be directed to the NHS body concerned.
- d) The HOSC is requested to consider and note the items within the proposed Work Programme and to suggest any additional topics to be considered for inclusion on the agenda of future meetings.

2. Recommendation

The Health Overview and Scrutiny Committee is asked to consider and note the report.

Background Documents

None

Contact Details

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Work Programme - Health Overview and Scrutiny Committee

1. Items scheduled for upcoming meetings

8 June 2021		
Item	Item background	Substantial Variation?
Covid-19 update	To receive an update on the response of local health services to the ongoing pandemic.	No
Healthwatch Kent and Medway – “Pharmacies and Covid: the reality”	To receive an update on the response of local community pharmacies to the pandemic	No
Ophthalmology Services	To discuss a possible change in provider for the service.	To be determined

2. Items yet to be scheduled

Item	Item Background	Substantial Variation?
Single Pathology Service in Kent and Medway	Members requested an update at the “appropriate time” during their meeting on 22 July 2020	No
East Kent Maternity Services	Following the discussion on 17 September 2020, Members requested the item return once the Kirkup report has been published.	-
East Kent Hospitals University NHS Foundation Trust - Covid-19 update	Following the discussion on 17 September 2020, Members requested the Trust return with an update on their response to the pandemic and the CQC inspection.	-
Provision of Child and Adolescent Mental Health Services at the Cygnet Hospital in Godden Green	To receive an update on the closure of the Tier 4 CAMHS service following the internal investigation by NHS England.	-

Item 8: Work Programme (4 March 2021)

Children and Young People’s Emotional Wellbeing and Mental Health Service - update	Members requested an update at the “appropriate time” during their meeting on 24 November 2020.	-
Orthotic Services and Neurological Rehabilitation	To receive information on the provision of these services in Kent for adolescents.	-
The Kent & Medway CCG – 18 months on	An opportunity to review how the first 18 months of the new single CCG has gone.	-
Provider updates	To receive general performance updates from each of the main local providers.	-
Update on the implementation of an integrated Care System across Kent & Medway	To receive an update on the implementation of ICSs, including Integrated Care Partnerships and Primary Care Networks.	-
Update on the implementation of hyper-acute stroke units	Following a discussion at their meeting on 22 September 2020, HOSC asked for an update “at the appropriate time”.	-

3. Items that have been declared a substantial variation of service and are under consideration by a joint committee

Kent and Medway Joint Health Overview and Scrutiny Committee		
NEXT MEETING: 17 March 2021		
Item	Item Background	Substantial Variation?
Transforming Health and Care in East Kent	Re-configuration of acute services in the East Kent area	Yes
Specialist vascular services	A new service for East Kent and Medway residents	Yes
Changes to mental health provision (St Martin’s Hospital)	KMPT’s plans for the St Martin’s (west) former hospital site, under their Clinical Care Pathways Programme	Yes