

COVID-19

What is the picture for people
with Learning Disabilities in Kent
and Medway?

Data correct as at 23/05/2020

Report

The purpose of this report is to prioritise action that might save people's lives, especially in places where people have symptoms of Covid-19.

We have looked across 15 rapid LeDeR reviews about people with Learning Disabilities who have died from Covid-19 to understand learning from these deaths. These are not full reviews and only give a snapshot about a small part of people's experience during this pandemic.

The learning from these deaths should be used:

- To make changes and prepare for a possible second wave of Covid-19 and
- To protect those people who currently have symptoms, and live or work in care homes and supported living services.

The learning covers:

- Testing and symptoms
- Testing and where people live
- Transmission and support
- Aloneness

Recommendations are given at the end.

Notes and limitations

- **The living**

Data about those with symptoms/suspected or confirmed C-19 is taken from the KCC Sit Rep at the end of each week, this doesn't include Supported Living or people who have Direct Payments.

People from Medway are not included

People in Acute and Mental Health Hospitals are not included

- **The dead**

LeDeR Rapid reviews began in the first week of April. This is where the information about the people who have died from Covid-19 is from.

People's deaths are mapped based on the postcodes for where they lived, not where they died.

These are only deaths where people have directly died from the Covid-19.

This mapping does not include people who might have died as a result in any part from the lockdown measures (for example death by suicide).

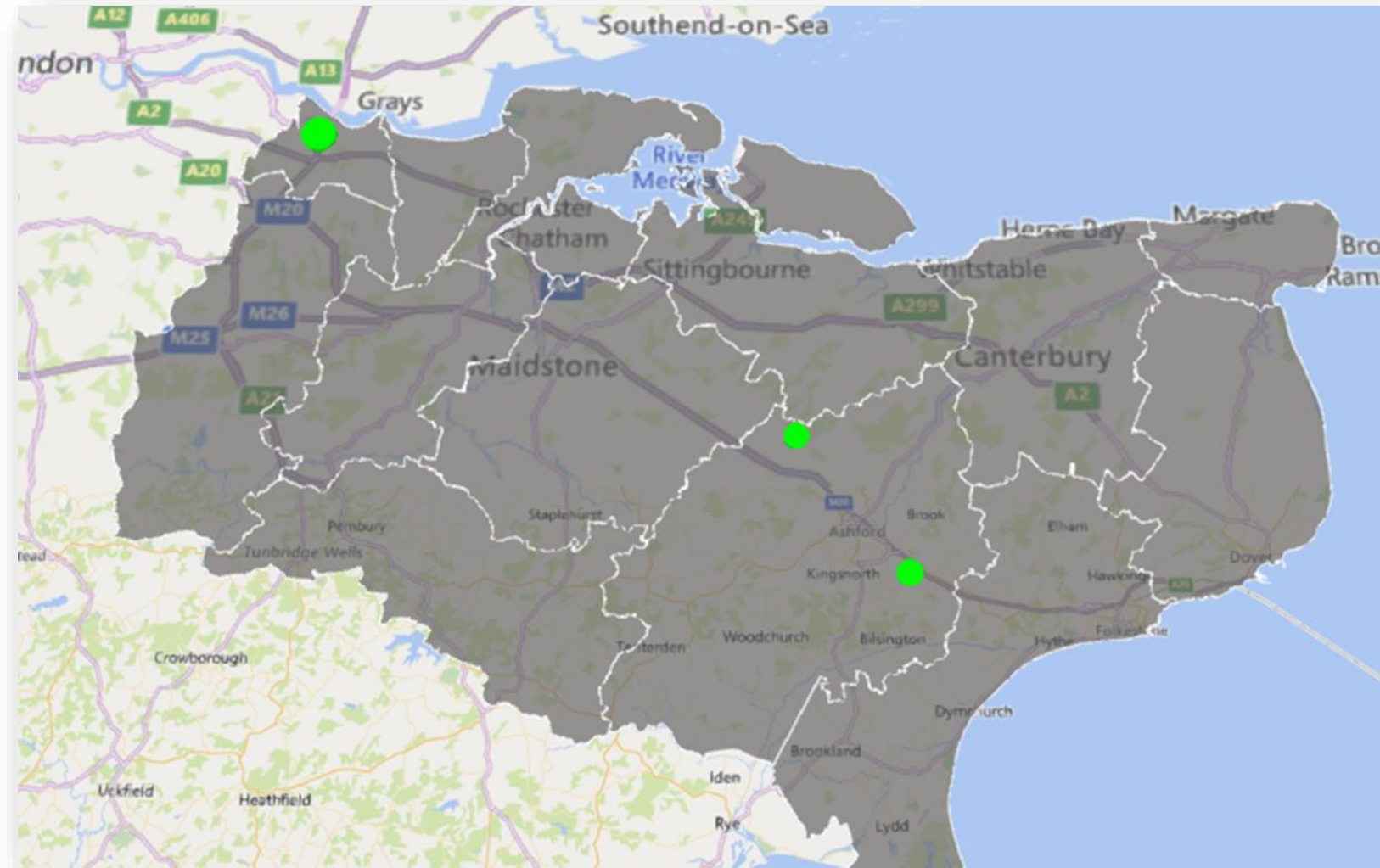
There is not very much information about carers who have symptoms or have died from COVID-19.



We think these people should be checked on more because we don't know a lot about Covid-19.

Recovered from Covid

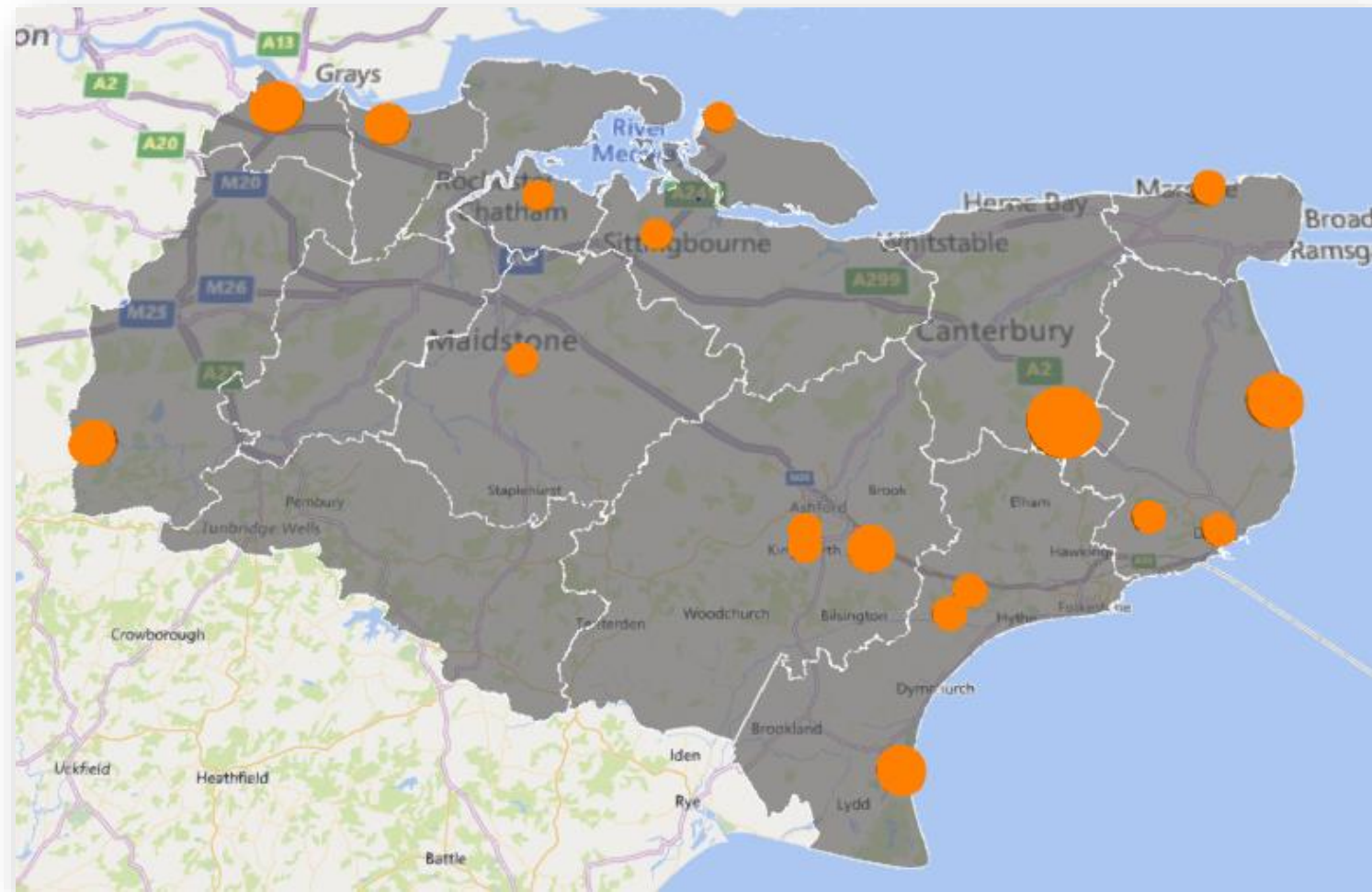
5 people with learning disabilities

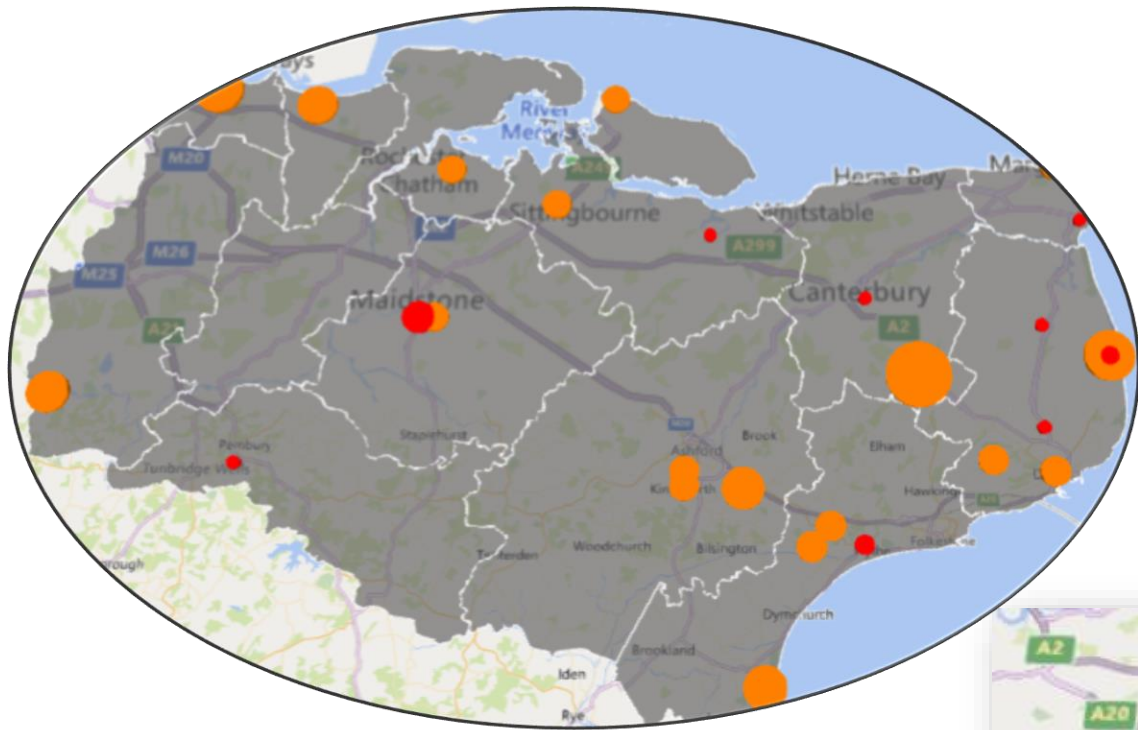


Symptomatic or suspected Covid-19

All 31 of these people are at Learning
Disability care Homes.

21 people live there, and 10 people are
working in them.



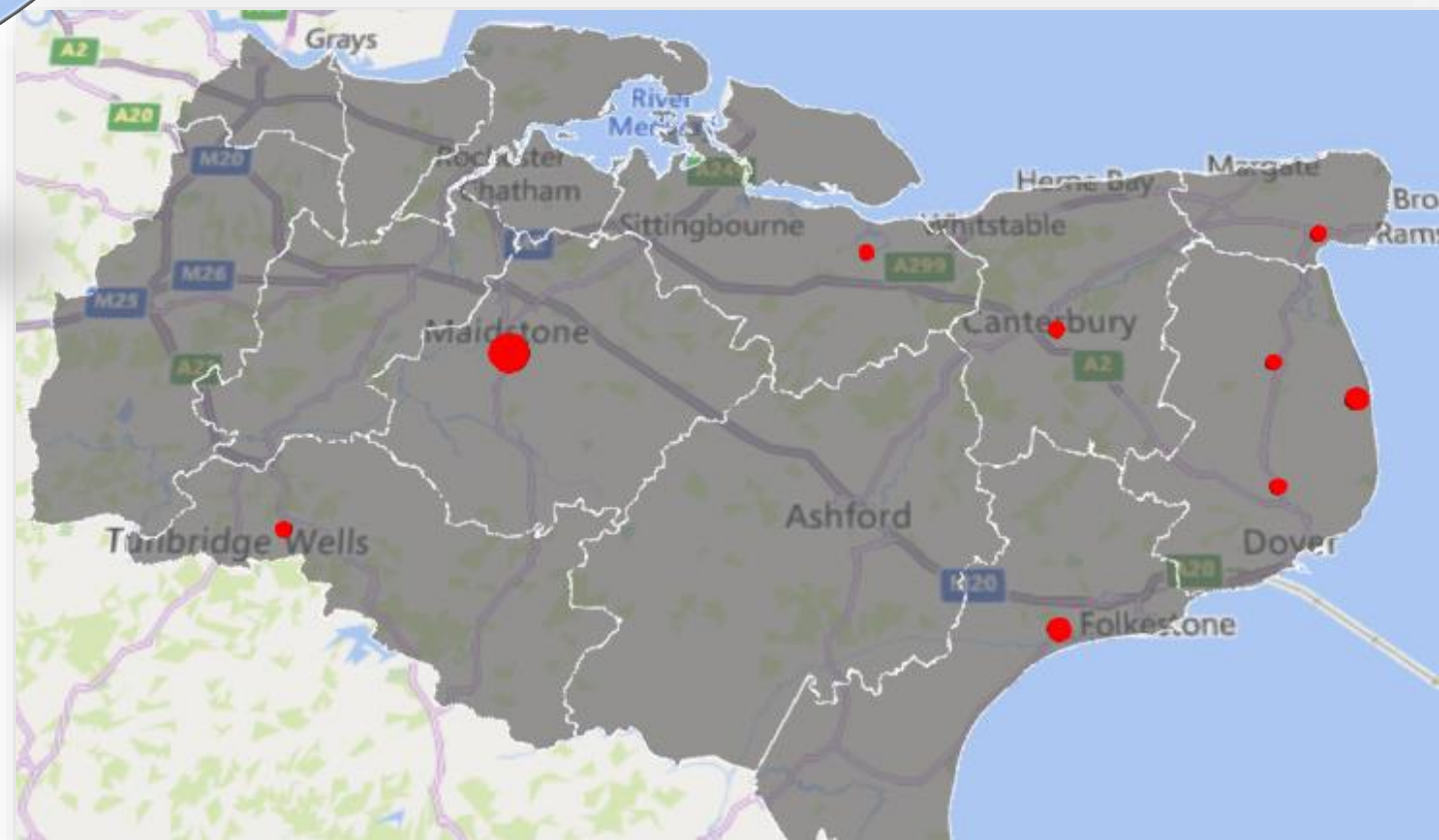


Confirmed

11 people testing positive for Covid-19 including less than 5 staff

All of the postcodes where these people live are Learning Disability care Homes.

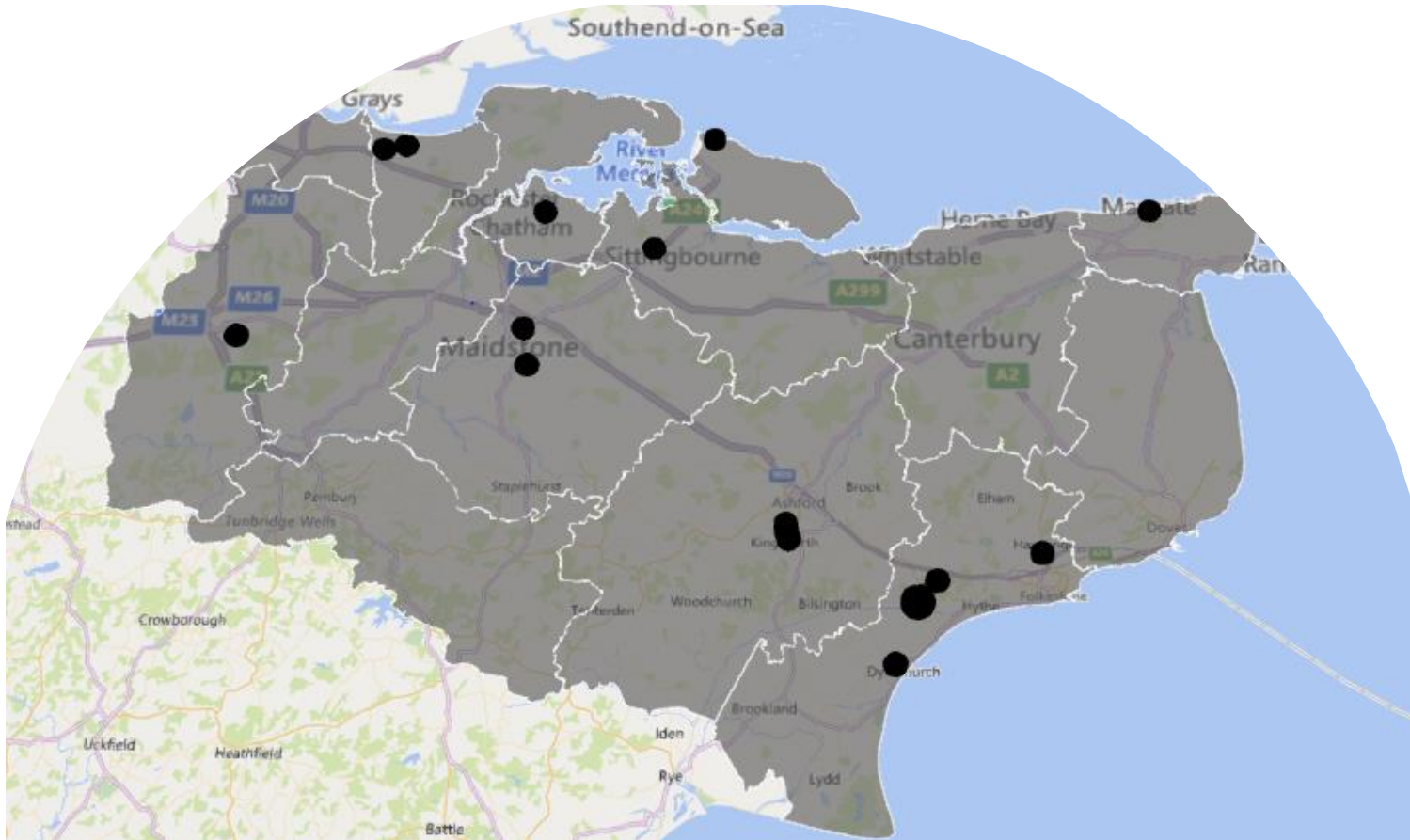
It would be helpful to understand how people got access to testing as they do not easily overlap with suspected cases (orange)





Deaths from Covid-19

15 people with learning disabilities have died from COVID-19, and had a Rapid Review completed across Kent and Medway



Testing & symptoms

Tests happened after emergency admission to Hospital. 8 people tested positive for Covid-19.

For all 8 people, when symptoms became visible to care staff, 999 & admission through A&E was needed. 5 people died within 3-6 days, others who lived longer lived for up to 2 weeks.

Less than 5 people were already in hospital and all died within 4 days of being tested.

In all 15 rapid reviews when breathlessness, high temperature and/or cough was noted they quickly became very unwell. Less than 5 people did **not** have breathlessness noted when COVID-19 was considered.

In 8 cases there was some other healthcare intervention delivered, including people being prescribed antibiotics.

There were no reports of lost taste or smell. All symptoms noted were observed by carers.

Testing & where people live

All 8 people tested, and most people who died from COVID-19 lived in congregate care settings.

Most were living in Care homes. Less than 5 people were living at the same care home. Less than 5 people lived in Supported Living.

Less than 5 people lived in family homes.

Whilst this is small numbers of people, this is clear evidence that people are more at risk of getting Covid-19 when they live in congregate settings.

National testing excludes all homes that are not for Older People.

PHE Testing is for people who are symptomatic, or living with someone who is.

Transmission and support

Almost everyone caught Covid-19 in the community where they lived.

For less than 5 people it's not clear if they caught Covid-19 in the community or Hospital.

At least 1 appears to have caught COVID-19 in hospital.

Shielding - There was nothing noted in anyone's rapid reviews about anyone being shielded. Less than 5 People had conditions that may have met the criteria for shielding

Almost all rapid reviews for people who lived in care homes or supported living recommended that bereavement support was needed for carers.

Carers had difficulty telling one person's housemates that they had died.

It was clear from the tone of the reviews that carers felt uncomfortable about people in their care having caught covid-19.

Aloneness

This is a theme that tells us about how people experienced life beyond care during covid-19, as well people's experience of death.

Life:

80% of people were recorded as being "single (never married)", for 20% it was recorded as "not known".

This means that none of the people who died were known to have a partner in life.

Age at death:

The oldest person who died was 88, and the youngest was 40 years old.

The average was for death 62 years old. Less than 5 people who died were over 70.

Aloneness - continued

Care experience

5 people had hospital passports, but some were not up to date. People who were in Elderly Care Homes did not have Hospital Passports.

Some people also needed Communication passports but it's not clear whether these are consistently in place or used.

“No next of Kin”, “not known” or nothing was noted regarding next of kin in most rapid reviews. No next of kin was noted in one case, despite the person living with a family for their entire life.

7 people had DNAR decision made in hospital, for less than 5 people it is clear that family were involved. 5 people were also put on EoL pathway.

Less than 5 people had DNAR decision in the community, and all had family involved in these discussions.

In 5 cases, nothing is noted, or it is not clear what conversation happened regarding End of Life care and DNAR.

Aloneness - continued

Death:

Out of the 12 people who died in hospital just 1 person was supported to have familiar people with them in their final moments. This person had been in hospital since before the Covid-19 outbreak.

Less than 5 people were discharged from hospital to die at hospice or at home. Only 1 person who was discharged to their care home had someone who knew them well with them in their final moments.

Almost everyone was either alone, or with people who were not familiar to them in their final moments alive.

Recommendation 1:

People in Supported Living and Care Homes should have their Oxygen saturation levels checked as regularly as their temperature.

Most people with learning disabilities who died from COVID-19 were cared for and did not self report one of the key symptoms (loss of taste and smell).

All Providers of care are taking steps to protect and check for symptoms of COVID-19, including temperature checks regularly.

Antibiotics were prescribed in some cases where covid-19 could have been considered or looked for.

When symptoms of Covid-19 were seen by carers and recognised by health professionals, people became very unwell very quickly.

One symptom of COVID-19 is silent Hypoxia. This can be monitored by care staff with an Oximeter with oversight from the GP, or the community learning disability team.

Recommendation 2:

Care Homes and Supported Living services should be enabled to access testing for COVID-19.

People with learning disabilities in supported living and care homes are dependant on carers coming in and out of their home to help them, and in many cases to recognise symptoms of Covid-19.

The national guidance should be challenged and changed to include all care homes and supported living.

Where staff have symptoms, they should be included in understanding whether there is an outbreak of COVID-19 at a care setting, and regarded as 'someone you live with who has symptoms' in order to access testing.

Where local action takes time to arrange, Providers of Care to people with Learning Disabilities should be encouraged to access testing for their staff on a weekly basis.

Recommendation 3:

Carers, families and people in receipt of care should have side by side access to good quality bereavement and trauma support.

This should be open, freely accessible and not segregated.

Paid and unpaid carers, people with learning disabilities, family members and friends are all experiencing the COVID-19 pandemic, and the effects of the lockdown measures, and adapting quickly to change together.

Providers of Social Care have employee assistance support available to staff. However reviews highlight the need for people receiving services to be able to access support too.

Community and voluntary sector partners, providers, and self advocates have been open in talking about feelings of fear, abandoned, being unsafe, trapped, invalidated, powerless and under threat during the last 9 weeks.

Partnership Board Advocacy Group NKIAS and the Chairs of the Good Health Group, have offered to create and widen local groups that are running virtually into peer support groups as an additional, recognised avenue of support.

Recommendation 4:

People should be actively supported across the system to have loving relationships.

Regardless of age people with learning disabilities died without having had a life partner, or people who cared for them did not know.

Many people appear to have limited contact with family (no next of kin”, or “not known”).

Research by the founder of Supported Loving shows that particularly for people who have minimal contact with family, their partner provides companionship and emotional closeness.

[The Mental Health Foundation](#) explains that having good-quality relationships can help us to live longer and happier lives with fewer mental health problems; that loneliness and isolation remain the key predictors for poor psychological and physical health.

Having a lack of good relationships and long-term feelings of loneliness have been shown by a range of studies to be associated with higher rates of mortality, poor physical health outcomes and lower life satisfaction.

Loving relationships needs to be a priority strategic outcome to be pursued across Kent and Medway with people with learning disabilities and autism.

Recommendation 5:

People should be supported to have people who are familiar to them with them when they are dying.

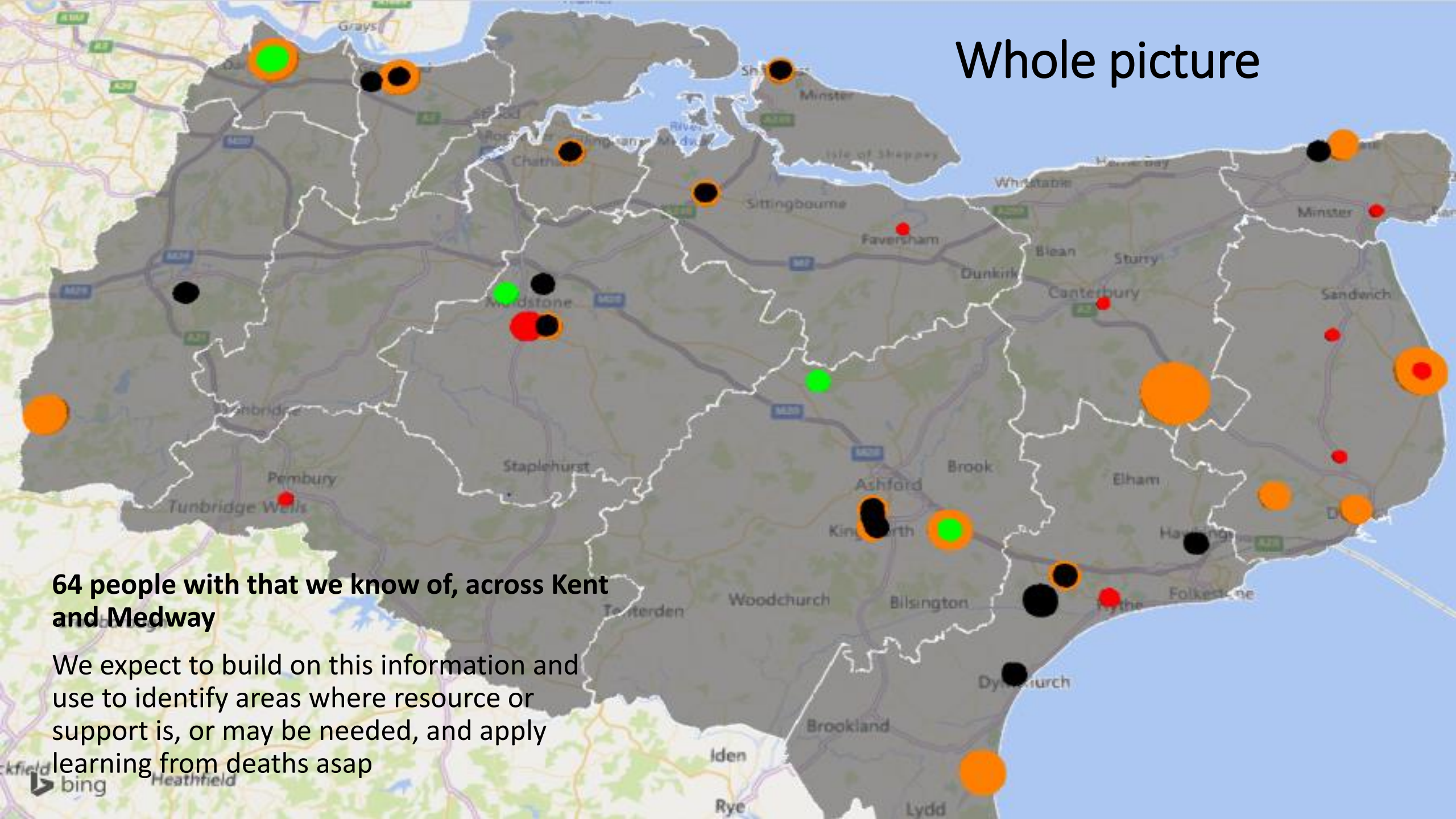
There has been a lot of conversation about visiting people at hospital, and yet almost everyone died alone in hospital.

The [Hospital visiting guidance](#) says that a family member or carer can visit where people are dying, and where a person has a learning disability, autism or mental health need and could be in distress without familiarity.

Hospitals should be clear and proactive about making sure this guidance is followed.

Providers of care, and community and voluntary organisations will be made aware of this so that people know their rights.

Whole picture



64 people with that we know of, across Kent and Medway

We expect to build on this information and use to identify areas where resource or support is, or may be needed, and apply learning from deaths asap