



# Health books and health passports



**What adults with learning disabilities in Norfolk say about using them**



# Health book and health passport research survey

**Questions**

1. What do you think about it?

☐ Good

☐ Bad

☒ Not sure

We made questionnaires and writing sheets for people to tell us about their experiences of health books and health passports.



From July to October we visited groups to run discussion workshops.

We also gave out questionnaires for people to fill in on their own.



We spoke to **81 adults with learning disabilities** living in Norfolk.

<p>West Norfolk CCG</p> <p> 13 people</p>	<p>Norwich CCG</p> <p> 19 people</p>	<p>North Norfolk CCG</p> <p> 17 people</p>
<p>South Norfolk CCG</p> <p> 13 people</p>	<p>Great Yarmouth and Waveney CCG</p> <p> 19 people</p>	



# What we found out

About who has a health passport or health book in Norfolk

 <div>27</div>  <p>I have a health book</p>	 <div>28</div>  <p>I have a health passport</p>	 <div>22</div>  <p>I do not have either</p>
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## Distribution of health books

West CCG	South CCG	Norwich CCG	North CCG	Great Yarmouth & Waveney CCG
3	2	8	12	2

## Distribution of health passports

West CCG	South CCG	Norwich CCG	North CCG	Great Yarmouth & Waveney CCG
4	1	3	2	18



Some people did not know if they had either of them




Some people had both a health book and a health passport



# What we found out

Why people think it is good to have a health book or health passport

 <p>Helps with all communication about my health</p> <p> 23 people</p>	 <p>Helps with my health when I am in hospital</p> <p> 15 people</p>
 <p>Gives doctors and nurses the right information about me</p> <p> 10 people</p>	 <p>Helps me to deal with problems about my health</p> <p> 8 people</p>
 <p>Shows what medications I take</p> <p> 6 people</p>	 <p>Helps me to understand and speak up about my health</p> <p> 5 people</p>



I write my weight in there to keep track of it



Helps me tell people when I am unwell















I take my health book on my holidays with me



# What we found out


Getting and updating health books and health passports

## Where I got my health book or health passport

<p>GP surgery</p>   <p>2 people</p>	<p>LD Nurse or hospital</p>   <p>5 people</p>	<p>Day services</p>   <p>20 people</p>
<p>Opening Doors</p>   <p>3 people</p>	<p>Family member</p>   <p>2 people</p>	<p>I do not know</p>   <p>3 people</p>



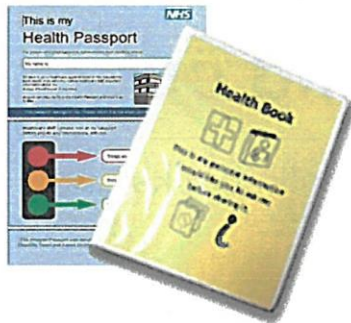
Where people who do not have a health book or health passport think they could get one

<p>Chemist</p>  <p>Pharmacy</p>	<p>NHS</p> 	<p>Dentist</p>  <p>Dentist</p>	<p>Support Staff</p> 	<p>Do not know</p> 
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## Is your health book or health passport kept up-to-date?

  <p>14 people</p>	  <p>18 people</p>	  <p>20 people</p>
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# What we found out

About storing and using a health book or health passport



## Where I keep my health book or health passport

At home



36 people

LD Nurse or hospital



2 people

Day services



22 people

Always in my bag



1 person

Family keep it



2 people

Staff keep it



5 people



My staff have mine and they look in it



I always have my health book with me



Mine is locked away in the office



# What we found out

About storing and using a health book or health passport



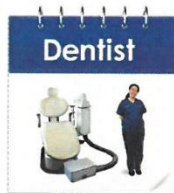
## Where I take my health book or health passport

To my GP



11 people

To the dentist



6 people

To hospital



10 people

Always in my bag



1 person

Family keep it



2 people

Staff keep it



5 people



I take it to my Rheumatology appointments



Ambulance staff asked if I had one so I gave it to them



I took mine to with me to wheelchair services





# What we found out

About using health books and health passports with health professionals



Who writes in my health book or health passport or supports me to fill it in

Staff and supporters



12 people

Friends and family



11 people

GP



6 people

Advocate



2 people

Police



1 person

Social worker



1 person

Day service staff



12 people

Learning Disability nurse



9 people

I do not know



4 people





# What we found out

About using health books and health passports with health professionals



People who do not have a health book or health passport told us who else they *think* would write in them

Psychologist



2 people

Optician



1 person

Care Staff



2 people

Opening Doors staff



2 people

Keyworker



1 person

Paramedics



1 person

My book is empty



2 people

I have a health book or health passport that no-one has written in

I will not write in it



9 people

Health professionals have said no to writing in my health book or health passport



# What we found out

Problems with using health books and health passports



## Difficulties I have using a health book or health passport

It is hard to understand



13 people

I do not get to see mine



2 people

I cannot read



2 people

I can only use it with support



2 people

Health people write big words in it



1 person

It is not easy read with good pictures



1 person



## How it makes me feel when people will not write in my health book or health passport

Cross and frustrated



6 people

Sad and upset



11 people

Scared and worried



2 people























# What we found out

Replacing or refilling health books and health passports



Who I would ask for help if my health book or health passport was lost or running out of pages

<p>Staff and supporters</p>   <p>2 people</p>	<p>Family</p>   <p>2 people</p>	<p>GP</p>   <p>2 people</p>
<p>I would photocopy it myself</p>   <p>1 person</p>	<p>Police</p>   <p>1 person</p>	<p>Social worker</p>   <p>1 person</p>
<p>Day service staff</p>   <p>1 person</p>	<p>Opening Doors</p>   <p>2 people</p>	<p>The learning disability team</p>   <p>4 people</p>





# Other comments people told us



Quite a lot of people told us they did not understand what a health book or health passport was or how to use it.



Of the people we heard from **15 people** who do not have a health book or health passport said they would like one.



Some people told us they would use a health book or health passport if they could have it on a tablet or a phone.



This report is by self advocates from Opening Doors, with support from Healthwatch Norfolk.

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