



**Professional
Record
Standards
Body**

**Better records
for better care**

DIABETES INFORMATION RECORD STANDARDS

**SURVEY RESULTS AND ANALYSIS v 1.0
JANUARY 2022**

Document Management

Revision History

Version	Date	Summary of Changes
0.1	20.12.2021	First draft created
0.2	16.05.2022	Updated following project team and assurance committee review
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Glossary of Terms

Term / Abbreviation	What it stands for
AMHT	Adult Mental Health Team
CCG	Clinical Commissioning Group
CGM	Continuous Glucose Monitoring
CMHT	Children's Mental Health Team
COVID-19	Coronavirus Disease 2019
DIY	'Do It Yourself'
DKA	Diabetic Ketoacidosis
DSN	Diabetic Specialist Nurse
GP	General Practitioner
HbA1c	Haemoglobin A1c
HCP	Healthcare Professional
HCW	Health or Care Worker
HHS	Hyperosmolar Hyperglycaemic State
IAPT	Improving Access to Psychological Therapies
IG	Information Governance
IS-CGM	Intermittent Scanning – Continuous Glucose Monitor(ing)
ISN	Information Standards Notice
IT	Information Technology
LADA	Latent Autoimmune Diabetes in Adults
NDA	National Diabetes Audit
NDPP	NHS Diabetes Prevention Programme
NHS	National Health Service
NHSE/I	NHS England and NHS Improvement
NICE	National Institute for Health and Care Excellence
PCSP	Personalised Care and Support Plan
PDF	Portable Document Format
PRSB	Professional Record Standards Body
PROMS	Patient Reported Outcome Measures
PREMS	Patient Reported Experience Measures
PWD	Person/ People with Diabetes
PWDT1	Person/ People with Type 1 Diabetes
PWDT2	Person/ People with Type 2 Diabetes
QOL	Quality of Life
RT-CGM	Real Time – Continuous Glucose Monitor(ing)
RWD	Real World Data

SNOMED CT	Systemized Nomenclature of Medicine – Clinical Terms
T1DM	Type 1 diabetes mellitus
T2DM	Type 2 diabetes mellitus

Planned Review Date and Route for User Feedback

The next maintenance review of this document is planned for February 2025, subject to agreement with NHS England and NHS Improvement as the commissioning body.

Please direct any comments or enquiries related to the project report and implementation of the standard to support@theprsb.org

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1 Introduction and methods

1.1 Introduction

This is an appendix to the final report for the diabetes information record standards project.

The two online surveys (including a main survey and an easy read version) were part of a wider consultation for health and social care workers and professionals, people with diabetes (PWD) and clinical systems suppliers. The questionnaires were intended to gather qualitative and quantitative data to inform the further development of the following draft project deliverables including:

1. **A diabetes record standard:** for a person-centred record about a person with diabetes for use across health and care settings.
2. **A self-reported data standard:** for sharing information collected by people with diabetes at home with healthcare professionals, such as blood pressure or from wearable devices such as continuous glucose monitors.
3. **A 'view' of the personalised care and support plan (PCSP) standard:** to define the information required for care planning for people with diabetes.

1.2 Methods

The main diabetes survey ran from 11 September 2021 – 11 December 2021 and generated 511 responses. Following cleaning of the dataset (involving removal of duplicate and inadequately completed entries) a total of 280 participant responses were included in the final analysis.

1.3 What the survey was

- For testing the content of the diabetes standards with the people who will use them by gathering evidence to support/ oppose the inclusion of existing sections, elements, and codes and to identify any new areas to incorporate as required.
- To better understand issues that may affect the implementation of the standards in the real world and the potential impact on people who will use them.
- A short and pragmatic exercise to engage stakeholders including people living with diabetes, the front-line health and care workers (HCWs) who care for them and people developing diabetes devices, apps/ applications, and systems.
- A process where the number of responses was necessarily constrained by the focus on a limited number of conditions (type 1, type 2 and other forms of diabetes mellitus) although a strength was that over 85% of respondents were either people with lived experience of diabetes or professionals with a special interest in diabetes care.

1.4 What this survey was not

- Designed to gather detailed participant characteristics (e.g., age, sex, or other potentially confounding factors) or generate conclusions about PWD themselves. Caution should be applied when drawing inferences that may not be generalisable to the wider population of PWD in UK. The information gathered may be representative of the views of some or even many people living with diabetes, but it was not the intention of this exercise to draw conclusions beyond those relevant to guiding us in the development of the standards' content.

2 Survey respondents

2.1 Overall participants

A breakdown of survey participants is presented in table 1.

Key points

- 85% of participants were either people with diabetes (45.0%, n=126) or frontline health or care workers (40.0%, n=112).
- The other participants included system suppliers (2.50%, n=7), parents or carers of people with diabetes (3.57%, n=10), people with prediabetes (2.86%, n=8), and other (6.07%, n=17).

Table 1 - Survey Participants

Participants	Percentage	n
Person with diabetes (PWD) or carer answering on their behalf	45.0%	126
Frontline health or care worker (HCW)	40.0%	112
System supplier *	2.50%	7
Parent or carer of person with diabetes	3.57%	10
Person with prediabetes	2.86%	8
Other **	6.07%	17
<i>Total</i>	<i>100%</i>	<i>280</i>

* Systems suppliers generally had a special interest in diabetes and included specialists in diabetes management systems (n=3), electronic record systems (n=2), diabetes medical devices (n=1) and apps (n=1).

** Respondents in the other category included PWD who were also frontline HCWs (n = 2), people with a history of gestational diabetes (n = 1), diabetes specialist nurse (n = 1), commissioners and service managers (n=3), charity worker (n=1), diabetes audit manager (n=1), diabetes devices education & training worker (n=1), diabetes data and digital representative (n=4), patient body representative (n=1), professional body representative (n=1) and other healthcare worker (n=1).

2.2 Participants with diabetes by type

Key points

- Most adult participants with diabetes (96.1%, n=124) had either type 1 (67.4%, n=87) or type 2 (28.7%, n=37) diabetes mellitus (T1DM and T2DM respectively).
- All children of parent respondents were living with T1DM (100%, n=8).
- Other types of diabetes represented were gestational diabetes (1.55%, n=2), monogenic diabetes (0.775%, n=1), latent autoimmune diabetes in adults (LADA) (0.775%, n=1) and unspecified (0.775%, n=1).

Table 2 – Participants with diabetes by type

Diabetes type	Percentage	n
<i>Adults with diabetes (person or carer respondent)</i>		
Type 1	67.4%	87
Type 2	28.7%	37
Gestational (history of)	1.55%	2
Other*	1.55%	2
Unspecified	0.775%	1

<i>Total</i>	100%	129
<i>Children with diabetes (parent respondent)</i>		
Type 1	100%	8
Type 2	0.00%	0
Other	0.00%	0
<i>Total</i>	100%	8

* Respondents in the adult other category included people with monogenic diabetes (n=1 and latent autoimmune diabetes in adults (LADA) (n=1). In addition, two carers for PWD (type 2) answered from their own perspective.

2.3 Participants with comorbidity by diabetes type

A breakdown of participants with comorbidity by diabetes type is presented in table 3.

Key points

- Most adult participants with type 1 (62.1%, n=54) and type 2 (75.7%, n= 28) diabetes were living with multimorbidity ('the presence of two or more long term health conditions.'¹).
- The demographics and comorbidity status of people with diabetes who participated in our survey are not necessarily generalisable to the wider population but a UK population-based study of 637,255 people with type 2 diabetes (PWDT2) found similarly that 77% were living with at least one comorbidity.²
- Half of the children of parent respondents (50.0%, n=4) were living with diabetes and at least one other long term health condition.

Table 3 – Participants with comorbidity by diabetes type

Diabetes type	Percentage	n
<i>Adults with type 1 diabetes (person or carer respondent) *</i>		
Living with one self-reported comorbidity	28.7%	25
Living with 3+ long term conditions	33.3%	29
Not living with self-reported comorbidity	37.9%	33
<i>Total</i>	100%	87
<i>Adults with type 2 diabetes (person or carer respondent) **</i>		
Living with one self-reported comorbidity*	29.7%	11
Living with multimorbidity (2+ long term conditions)	45.9%	17
Not living with self-reported comorbidity	24.3%	9
<i>Total</i>	100%	37
<i>Children with type 1 diabetes (parent respondent) ***</i>		

¹ NICE CKS. Multimorbidity. NICE Clinical Knowledge Summaries: 2018, Online. [Accessed January 2022]

² Zghebi S and others. Eleven-year multimorbidity burden among 637 255 people with and without type 2 diabetes: a population-based study using primary care and linked hospitalisation data. BMJ Open: 2020 [Accessed January 2020]

Living with one self-reported comorbidity	50.0%	4
Not living with self-reported comorbidity	50.0%	4
<i>Total</i>	100%	8

* Comorbidities reported in respondents with type 1 diabetes included endocrine disease (n=17), respiratory conditions (n=14), cardiovascular disease (n=12), neurological disease (n=10), rheumatological disease (n=10), gastroenterological disease (n=7), renal disease (n=5), mental health conditions (n=5), immunological conditions (n=4), dermatological conditions (n=3), diabetic eye disease (n=3), and other (n=5).

** Comorbidities reported in respondents with type 2 diabetes included cardiovascular disease (n=16), rheumatological disease (n=9), neurological disease (n=6), mental health conditions (n=6), endocrine disease (n=4), gastroenterological disease (n=4), respiratory conditions (n=4) and other (n=7).

*** Comorbidities reported in children with type 1 diabetes were coeliac disease (n=2), migraines (n=1), and hypothyroidism (n=1).

2.4 Frontline health or care workers by role

A breakdown of respondents by frontline health or care role is presented in table 4.

Key points

- Of 112 frontline health or care workers the majority (96.4%, n=108) were healthcare professionals (HCPs).
- 90% of respondents stated that they had a special interest in diabetes. Most professionals worked in secondary care (45.5%, n=51). The highest number of responses from secondary care was given by diabetologists (26.8%, n=30) and diabetic specialist nurses (DSNs) (10.7%, n=12). The number of GP respondents was low in comparison (6.25%, n =7) although contributions from practice nurses in GP surgeries (8.04%, n=9) strengthened the primary care perspective.
- Approximately one third of respondents were allied health professionals (30.4%, n=34) including podiatrists (20.5%, n=23) and dieticians (9.82%, n=11).

Table 4 – Participants by frontline health or care role

Role	Percentage	n
Hospital doctor (endocrinologist/ diabetologist/ specialist Diabetes Team)	26.8%	30
Allied health professions (Podiatrist)	20.5%	23
Nurse (Diabetic Specialist Nurse)	10.7%	12
Allied health professions (Dietitian)	9.82%	11
Nurse (Practice Nurse in GP surgery)	8.04%	9
GP	6.25%	7
Hospital doctor (Paediatrician)	3.57%	4
Hospital doctor (Anaesthetist)	1.79%	2
Hospital doctor (Emergency physician)	1.79%	2
Pharmacist	1.79%	2
Team (Hospital Diabetes Nurse Team)	0.893%	1
Team (Community Diabetes Care Team)	0.893%	1

Other	7.14%	8
<i>Total</i>	100%	112

* Respondents in the adult other category included Nurse consultant (n=1), Advanced diabetes nurse practitioner (n=1), Nurse practitioner in GP practice (n=1), Hospital doctor (orthopaedic surgeon) (n=1), Community palliative care consultant (n=1), Youth Worker (n=1), Healthcare assistant (n=1), and Executive director (n=1).

3 Summary comparisons

The responses to the individual survey questions are set out in section 4 below. Some responses have been grouped across all respondents, but the majority have been grouped into two categories: 1. People with type 2 diabetes, people with type 1 diabetes, parents of children with diabetes and carers and 2. Healthcare professionals, systems or medtech suppliers and others. For the two key questions in the survey, responses from people with diabetes and their carers or parents have been brought together with those of healthcare professionals to identify whether there is alignment in the information identified as needed:

- What information recorded at home for self-management should be shared with healthcare professionals to help them better provide advice and support? (see summary table A)
- What information about a person with diabetes is needed in the record to support care planning? (see summary table B)

Overall, there is good alignment between the information people with diabetes and their carers record for self-management and want to share with their healthcare professionals and the information that healthcare professionals need access to, to support the person. The main differences are that people with type 2 diabetes generally did not want to share information about insulin (however, the majority are unlikely to be using insulin), smoking status or family planning.

There are differences in views on the frequency with which the information should be shared. In general, but based on the very small sample in the survey, parents of children with diabetes want to share the information more frequently than others.

Likewise, there is good alignment between the information that people with diabetes and their carers think should be available about them to support the care planning process and the information that healthcare professionals have identified that they would need access to. The main differences are that people with type 2 diabetes do not consider it necessary for healthcare professionals to have access to information on family planning or safeguarding and risks to support care planning. There is not sufficient information to conclude why there are these differences, they may be because of confounding factors such as age or sex.

Summary table A - What information recorded at home for self-management should be shared with health and care professionals and at what frequency to help them better provide advice and support?

Information		Not at all %	Between appointments					At the time of appointments		After a significant event %	Other %	Total (n)
			Daily %	Weekly %	Monthly %	Annually %	In between appointments %	Before appointments %	At scheduled appointments %			
Blood sugar	T2	7.41	14.81	18.52	29.63	0	N/A	22.22	N/A	7.41	N/A	27
	T1	0	21.79	3.85	24.36	1.28	N/A	48.72	N/A	0	N/A	78
	P	0	42.86	14.29	14.29	0	N/A	28.57	N/A	0	0	7
	HCP	0.89	N/A	N/A	N/A	N/A	22.32	N/A	60.71	6.25	9.82	112
Episodes of hypoglycaemia	T2	17.39	8.7	0	21.74	4.35	N/A	13.04	N/A	34.78	N/A	23
	T1	4.11	12.33	6.85	13.7	1.37	N/A	30.14	N/A	31.51	N/A	73
	P	0	42.86	14.29	0	0	N/A	28.57	N/A	14.29	0	7
	HCP	1.8	N/A	N/A	N/A	N/A	17.12	N/A	54.05	18.02	9.01	111
Medications and allergies	T2	13.33	10	3.33	13.33	16.67	N/A	43.33	N/A	0	N/A	30
	T1	4.23	14.08	0	4.23	19.72	N/A	53.52	N/A	4.23	N/A	71
	P	0	42.86	14.29	0	0	N/A	42.86	N/A	0	0	7
	HCP	1.8	N/A	N/A	N/A	N/A	9.01	N/A	77.48	4.5	7.21	111
Insulin	T2	38.89	22.22	0	11.11	5.56	N/A	22.22	N/A	0	N/A	18
	T1	0	17.81	4.11	21.92	5.48	N/A	49.32	N/A	1.37	N/A	73
	P	0	42.86	14.29	14.29	0	N/A	28.57	N/A	0	0	7
	HCP	3.6	N/A	N/A	N/A	N/A	20.72	N/A	62.16	3.6	9.91	111
Physical activity	T2	7.41	18.52	0	18.52	11.11	N/A	44.44	N/A	0	N/A	27
	T1	15.38	13.85	6.15	12.31	7.69	N/A	43.08	N/A	1.54	N/A	65

	P	16.67	50	16.67	0	0	N/A	16.67	N/A	0	0	6
	HCP	8.04	N/A	N/A	N/A	N/A	8.04	N/A	75	0.89	8.04	112
Sleep	T2	16	12	4	16	4		48	N/A	0	N/A	25
	T1	19.7	12.12	4.55	9.09	10.61		43.94	N/A	0	N/A	66
	P	16.67	16.67	33.33	0	0		33.33	N/A	0	0	6
	HCP	30.91	N/A	N/A	N/A	N/A	3.64	N/A	45.45	6.36	13.64	110
Diet	T2	19.23	7.69	7.69	19.23	11.54	N/A	34.62	N/A	0	N/A	26
	T1	10.61	10.61	7.58	12.12	6.06	N/A	51.52	N/A	1.52	N/A	66
	P	14.29	14.29	28.57	0	0	N/A	42.86	N/A	0	0	7
	HCP	7.21	N/A	N/A	N/A	N/A	10.81	N/A	66.67	2.7	12.61	111
Questionnaires	T2	14.29	7.14	3.57	21.43	25	N/A	28.57	N/A	0	N/A	28
	T1	8.96	2.99	5.97	11.94	31.34	N/A	38.81	N/A	0	N/A	67
	P	14.29	0	0	14.29	0	N/A	71.43	N/A	0	0	7
	HCP	20.72	N/A	N/A	N/A	N/A	12.61	N/A	56.76	1.8	8.11	111
Mental health	T2	7.69	3.85	0	23.08	15.38	N/A	42.31	N/A	7.69	N/A	26
	T1	9.59	6.85	5.48	15.07	13.7	N/A	47.95	N/A	1.37	N/A	73
	P	0.00%	0.00%	0.00%	14.29	0	N/A	85.71	N/A	0	0	7
	HCP	3.57	N/A	N/A	N/A	N/A	8.93	N/A	75	1.79	10.71	112
Smoking status	T2	30	10	0	0	25	N/A	30	N/A	5	N/A	20
	T1	14.52	8.06	3.23	1.61	37.1	N/A	35.48	N/A	0	N/A	62
	P	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked
	HCP	2.7	N/A	N/A	N/A	N/A	0.9	N/A	89.19	1.8	5.41	111
Alcohol intake	T2	8	8	4	12	16	N/A	52	N/A	0	N/A	25
	T1	14.06	4.69	6.25	7.81	25	N/A	42.19	N/A	0	N/A	64
	P	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked
	HCP	0.89	N/A	N/A	N/A	N/A	1.79	N/A	87.5	2.68	7.14	112
Family planning / pregnancy	T2	80	10	0	0	0	N/A	10	N/A	0	N/A	10
	T1	21.43	3.57	0	7.14	17.86	N/A	50	N/A	0	N/A	56

	P	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked
	HCP	17.43	N/A	N/A	N/A	N/A	11.01	N/A	57.8	2.75	11.01	109
Measurements taken at home	T2	7.14	7.14	10.71	25	14.29	N/A	35.71	N/A	0	N/A	28
	T1	10.14	4.35	7.25	15.94	8.7	N/A	49.28	N/A	4.35	N/A	69
	P	0	0	0	0	0	N/A	100	N/A	0	0	7
	HCP	5.5	N/A	N/A	N/A	N/A	11.93	N/A	68.81	3.67	10.09	109
Foot checks	T2	7.14	7.14	0	25	17.86	N/A	39.29	N/A	3.57	N/A	28
	T1	4.23	1.41	4.23	19.72	15.49	N/A	43.66	N/A	11.27	N/A	71
	P	0	0	0	0	0	N/A	100	N/A	0	0	7
	HCP	8.04	N/A	N/A	N/A	N/A	13.39	N/A	72.32	0	6.25	112
Additional support services attended	T2	18.18	9.09	0	18.18	13.64	N/A	40.91	N/A	0	N/A	22
	T1	4.17	2.78	2.78	19.44	15.28	N/A	55.56	N/A	0	N/A	72
	P	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked
	HCP	8.18	N/A	N/A	N/A	N/A	12.73	N/A	68.18	1.82	9.09	110
Important information about the person	T2	10.71	3.57	7.14	10.71	28.57	N/A	35.71	N/A	3.57	N/A	28
	T1	1.45	5.8	2.9	15.94	33.33	N/A	39.13	N/A	1.45	N/A	69
	P	0	0	0	14.29	0	N/A	85.71	N/A	0	0	7
	HCP	1.79	N/A	N/A	N/A	N/A	10.71	N/A	75.89	1.79	9.82	112
Goals and progress against them	T2	6.9	13.79	6.9	6.9	27.59	N/A	37.93	N/A	0	N/A	29
	T1	8.82	2.94	5.88	19.12	13.24	N/A	50	N/A	0	N/A	68
	P	0	0	0	14.29	0	N/A	85.71	N/A	0	0	7
	HCP	8.93	N/A	N/A	N/A	N/A	9.82	N/A	72.32	0.89	8.04	112

T2 = PWD with type 2 diabetes and carers of people with type 2 diabetes responding from the perspective of the people they care for. **T1** = PWD with type 1 diabetes and carers of people with type 1 diabetes responding from the perspective of the people they care for. **P** = parents of children with type 1 diabetes. **HCP** = Healthcare professional. **N/A** = Option was not available for selection. Values highlighted in **bold** are the most selected frequency.

Summary table B - What information about a person with diabetes is needed in the record to support care planning?

Information		Never %	Sometimes needed %	Nearly always needed %	Needed %	Total (n)
Demographics and contacts	T2	11.54	23.08	65.38	N/A	26
	T1	10.26	32.05	57.69	N/A	78
	P	0	0	100	N/A	8
	HCP	N/A	N/A	N/A	95.54	112
Legal information	T2	22.22	40.74	37.04	N/A	27
	T1	17.95	38.46	43.59	N/A	78
	P	0	25	75	N/A	8
	HCP	N/A	N/A	N/A	82.14	112
Social context: Smoking, alcohol, social circumstances, occupation, driving status	T2	15.38	42.31	42.31	N/A	26
	T1	8.97	35.9	55.13	N/A	78
	P	Not asked	Not asked	Not asked	Not asked	Not asked
	HCP	N/A	N/A	N/A	91.96	112
Pregnancy status: Pregnant or trying for a baby	T2	72.73	9.09	18.18	N/A	22
	T1	36.84	21.05	42.11	N/A	76
	P	Not asked	Not asked	Not asked	Not asked	Not asked
	HCP	N/A	N/A	N/A	75	112
Safeguarding and risks	T2	41.67	20.83	37.5	N/A	24
	T1	19.74	25	55.26	N/A	76
	P	0	0	100	N/A	8
	HCP	N/A	N/A	N/A	92.86	112
Medications and allergies	T2	18.52	7.41	74.07	N/A	27

	T1	2.63	7.89	89.47	N/A	76
	P	0	0	100	N/A	8
	HCP	N/A	N/A	N/A	94.64	112
Encounters: referrals (e.g. for structured education)	T2	18.52	14.81	66.67	N/A	27
	T1	3.9	29.87	66.23	N/A	77
	P	0	12.5	87.5	N/A	8
	HCP	N/A	N/A	N/A	91.96	112
Admission details	T2	15.38	11.54	73.08	N/A	26
	T1	3.85	20.51	75.64	N/A	78
	P	0	12.5	87.5	N/A	8
	HCP				98.21	112
Discharge details	T2	11.11	7.41	81.48	N/A	27
	T1	3.85	17.95	78.21	N/A	78
	P	0	0	100	N/A	8
	HCP	N/A	N/A	N/A	90.18	112
Investigation results (for example blood tests such as your haemoglobin A1c levels or urine tests related to diabetes)	T2	7.41	14.81	77.78	N/A	27
	T1	2.6	7.79	89.61	N/A	77
	P	0	0	100	N/A	8
	HCP	N/A	N/A	N/A	92.86	112
Examination findings (for example foot check or eye screening results)	T2	7.41	11.11	81.48	N/A	27
	T1	2.56	8.97	88.46	N/A	78
	P	25	12.5	62.5	N/A	8
	HCP	N/A	N/A	N/A	95.54	112
Measurements (for example blood pressure, heart rate or sugar levels)	T2	7.41	14.81	77.78	N/A	27
	T1	5.13	11.54	83.33	N/A	78
	P	0	0	100	N/A	8
	HCP	N/A	N/A	N/A	95.54	112
Assessments (for example questionnaires about diabetes or general health and wellbeing)	T2	7.41	18.52	74.07	N/A	27
	T1	3.85	25.64	70.51	N/A	78
	P	0	37.5	62.5	N/A	8

	HCP	N/A	N/A	N/A	86.61	112
Problem list (such as a diagnosis, abnormal test result, concerning symptom, or other health related issue)	T2	18.52	7.41	74.07	N/A	27
	T1	2.56	16.67	80.77	N/A	78
	P	0	12.5	87.5	N/A	8
	HCP	N/A	N/A	N/A	93.75	112
Procedures (operations or other therapies related to diabetes)	T2	14.81	7.41	77.78	N/A	27
	T1	5.13	14.1	80.77	N/A	78
	P	0	12.5	87.5	N/A	8
	HCP	N/A	N/A	N/A	91.07	112
Other plans and actions (agreed action for the healthcare professional or person or their carer to take)	T2	11.11	14.81	74.07	N/A	27
	T1	2.6	11.69	85.71	N/A	77
	P	0	12.5	87.5	N/A	8
	HCP	N/A	N/A	N/A	93.75	112

T2 = PWD with type 2 diabetes and carers of people with type 2 diabetes responding from the perspective of the people they care for. **T1** = PWD with type 1 diabetes and carers of people with type 1 diabetes responding from the perspective of the people they care for. **P** = parents of children with type 1 diabetes. **HCP** = Healthcare professional. **N/A** = Option was not available for selection. Values highlighted in **bold** are the most selected frequency.

4 Main survey content

4.1 On sharing information recorded at home with HCPs

People with diabetes and their carers or parents were asked variations of the following question:

'Which of the following information that could be recorded at home would you like to share with healthcare professionals, and how often? Any comments?'

Answers about which information should be recorded and shared with HCPs were selected from a pick list of 17 information categories for adults and 13 relevant for children (see table 5). Participants also identified how often each of these categories should be shared (see table 6). See table 6 for comments analysis.

Key points

- There was strong support for sharing this information recorded at home with healthcare professionals. At least 70% of responses in each group (PWDT1, PWDT2, parent of T1) supported the inclusion of at least 13 out of the 17 information categories.
- People with type 2 diabetes were least likely to want to share information about episodes of hypoglycaemia (68.9%, n=20), insulin dosing (44.4%, n=12), smoking (51.7%, n=15) and family planning (7.41%, n=2).
- People with type 1 diabetes were least likely to want to share information about sleep (65.1%, n=56), smoking (69.0%, n=60) and family planning (56.0%, n=47).
- Parents of children with diabetes were least likely to want to share information about sleep (71.4%, n=5) and physical activity (71.4%, n=5).
- The maximum number of parent respondents was small (n=8) and at least 70% of respondents selected yes to all 17 categories.

Table 5 – What information recorded at home do respondents want shared with HCPs?

Which of the following information that could be recorded at home would you like to share with healthcare professionals?						
Information	PWDT2		PWDT1* or other		Parents of T1	
	%Yes	n (total)	% Yes	n (total)	% Yes	n (total)
Blood sugar	75.76%	33	97.73%	88	100.00%	8
Episodes of hypoglycaemia	68.97%	29	90.91%	88	100.00%	8
Medications and allergies	87.50%	32	89.77%	88	100.00%	8
Insulin	44.44%	27	94.38%	89	100.00%	8
Physical activity	81.25%	32	70.00%	90	71.43%	7
Sleep	74.19%	31	65.12%	86	71.43%	7
Diet	74.19%	31	75.86%	87	85.71%	7

Questionnaires at home such as about how able the person is to look after themselves.	84.38%	32	79.31%	87	85.71%	7
Mental health	81.25%	32	86.21%	87	100.00%	8
Smoking status	51.72%	29	68.97%	87	Not asked	Not asked
Alcohol intake	73.33%	30	73.56%	87	Not asked	Not asked
Family planning / pregnancy	7.41%	27	55.95%	84	Not asked	Not asked
Measurements taken at home: e.g., blood pressure, blood or urine ketone tests, or body mass index (height and weight).	90.32%	31	83.53%	85	100.00%	8
Foot checks	83.87%	31	93.18%	88	100.00%	7
Additional support services attended	70.37%	27	90.59%	85	Not asked	Not asked
Important information about the person e.g. needs, preferences, concerns and wishes	87.50%	32	89.66%	87	100.00%	8
Goals and progress against them	93.33%	30	81.40%	86	100.00%	7

* This group also included a small number of participants with gestational and other types of diabetes as outlined in table 2. Two carers answered from their own perspective.

Key points

- Most people with diabetes and their parents wanted to share their information before an appointment with an HCP.
- Information sharing with an HCP 'before appointments' was the highest or joint highest selected response in most categories for both people with type 1 (88.2%, n=15) and type 2 (82.4%, n=14) diabetes.
- For parents, 'before appointments' was also the highest or joint highest selected response out of 13 categories (76.9%, n=10).
- Most people with type 1 diabetes wanted to shared insulin administration data 'before appointments' (49.3%, n=36) whereas most people with type 2 did not want to share this at all (38.9%, n=7).
- People with type 2 slightly favoured sharing blood sugar data 'monthly' (29.6%, n=8) over 'before appointments' (22.2%, n=6) and were equivocal about sharing smoking status either 'not at all' (30.0%, n=6) or 'before appointments' (30%, n=6).
- Sharing information about episodes of hypoglycaemia was favoured 'after a significant event' by both people with type 1 (31.5%, n= 23) and type 2 (34.8%, n= 8) diabetes.
- People with type 2 diabetes did not want to share family planning/ pregnancy information (80%, n= 8) although possible confounding factors include age, sex, and

fertility status (which were not collected in this survey) as well as a low response rate might explain this result.

- Parents most often wanted to share daily information about blood sugar (42.9%, n=3), episodes of hypoglycaemia (42.9%, n=3), insulin administration (42.9%, n=3), and physical activity (50.0%, n=3) although it is notable that the sample size was very small.

Table 6 – How often do respondents want information recorded at home shared with HCPs?

How often would you like to share this information with professionals?										
Information		Not at all %	Daily %	Weekly %	Monthly %	Annually %	Before appointments %	After a significant event %	Other %	Total (n)
Blood sugar	T2	7.41	14.81	18.52	29.63	0.00	22.22	7.41	N/A	27
	T1	0.00	21.79	3.85	24.36	1.28	48.72	0.00	N/A	78
	P	0.00	42.86	14.29	14.29	0.00	28.57	0.00	0.00	7
Episodes of hypoglycaemia	T2	17.39	8.70	0.00	21.74	4.35	13.04	34.78	N/A	23
	T1	4.11	12.33	6.85	13.70	1.37	30.14	31.51	N/A	73
	P	0.00	42.86	14.29	0.00	0.00	28.57	14.29	0.00	7
Medications and allergies	T2	13.33	10.00	3.33	13.33	16.67	43.33	0.00	N/A	30
	T1	4.23	14.08	0.00	4.23	19.72	53.52	4.23	N/A	71
	P	0.00	42.86	14.29	0.00	0.00	42.86	0.00	0.00	7
Insulin	T2	38.89	22.22	0.00	11.11	5.56	22.22	0.00	N/A	18
	T1	0.00	17.81	4.11	21.92	5.48	49.32	1.37	N/A	73
	P	0.00	42.86	14.29	14.29	0.00	28.57	0.00	0.00	7
Physical activity	T2	7.41	18.52	0.00	18.52	11.11	44.44	0.00	N/A	27
	T1	15.38	13.85	6.15	12.31	7.69	43.08	1.54	N/A	65
	P	16.67	50.00	16.67	0.00	0.00	16.67	0.00	0.00	6
Sleep	T2	16.00	12.00	4.00	16.00	4.00	48.00	0.00	N/A	25
	T1	19.70	12.12	4.55	9.09	10.61	43.94	0.00	N/A	66
	P	16.67	16.67	33.33	0.00	0.00	33.33	0.00	0.00	6
Diet	T2	19.23	7.69	7.69	19.23	11.54	34.62	0.00	N/A	26
	T1	10.61	10.61	7.58	12.12	6.06	51.52	1.52	N/A	66
	P	14.29	14.29	28.57	0.00	0.00	42.86	0.00	0.00	7
Questionnaires	T2	14.29	7.14	3.57	21.43	25.00	28.57	0.00	N/A	28

	T1	8.96	2.99	5.97	11.94	31.34	38.81	0.00	N/A	67
	P	14.29	0.00	0.00	14.29	0.00	71.43	0.00	0.00	7
Mental health	T2	7.69	3.85	0.00	23.08	15.38	42.31	7.69	N/A	26
	T1	9.59	6.85	5.48	15.07	13.70	47.95	1.37	N/A	73
	P	0.00%	0.00%	0.00%	14.29	0.00	85.71	0.00	0.00	7
Smoking status	T2	30.00	10.00	0.00	0.00	25.00	30.00	5.00	N/A	20
	T1	14.52	8.06	3.23	1.61	37.10	35.48	0.00	N/A	62
	P	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	
Alcohol intake	T2	8.00	8.00	4.00	12.00	16.00	52.00	0.00	N/A	25
	T1	14.06	4.69	6.25	7.81	25.00	42.19	0.00	N/A	64
	P	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	
Family planning / pregnancy	T2	80.00	10.00	0.00	0.00	0.00	10.00	0.00	N/A	10
	T1	21.43	3.57	0.00	7.14	17.86	50.00	0.00	N/A	56
	P	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	
Measurements taken at home	T2	7.14	7.14	10.71	25.00	14.29	35.71	0.00	N/A	28
	T1	10.14	4.35	7.25	15.94	8.70	49.28	4.35	N/A	69
	P	0.00	0.00	0.00	0.00	0.00	100.00	0.00	0.00	7
Foot checks	T2	7.14	7.14	0.00	25.00	17.86	39.29	3.57	N/A	28
	T1	4.23	1.41	4.23	19.72	15.49	43.66	11.27	N/A	71
	P	0.00	0.00	0.00	0.00	0.00	100.00	0.00	0.00	7
Additional support services attended	T2	18.18	9.09	0.00	18.18	13.64	40.91	0.00	N/A	22
	T1	4.17	2.78	2.78	19.44	15.28	55.56	0.00	N/A	72
	P	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	Not asked	
Important information about the person	T2	10.71	3.57	7.14	10.71	28.57	35.71	3.57	N/A	28
	T1	1.45	5.80	2.90	15.94	33.33	39.13	1.45	N/A	69
	P	0.00	0.00	0.00	14.29	0.00	85.71	0.00	0.00	7
Goals and progress against them	T2	6.90	13.79	6.90	6.90	27.59	37.93	0.00	N/A	29
	T1	8.82	2.94	5.88	19.12	13.24	50.00	0.00	N/A	68
	P	0.00	0.00	0.00	14.29	0.00	85.71	0.00	0.00	7

T2 = PWD with type 2 diabetes and carers of people with type 2 diabetes responding from the perspective of the people they care for. **T1** = PWD with type 1 diabetes and carers of people with type 1 diabetes responding from the perspective of the people they care for. **P** = parents of children with type 1 diabetes. **N/A** = Option was not available for selection. Values highlighted in **bold** are the most selected frequency.

Key points

- The most highly cited themes in the comments mentioned that information should be shared when necessary to appropriate HCPs and indicated a willingness to share.

Table 7 – Summary of comments on sharing information recorded at home with HCPs

Comments on sharing information with HCPs			
Theme	Person (n)	Parent (n)	Key quote(s)
Frequency of sharing information:			<p>“Obviously the Libre data can be shared. It would save time if the HCP is made aware in advance what has and hasn't changed - especially in regard to behaviours such as smoking and drinking / family planning” – PWDT1</p> <p>“Medication and allergies should already be recorded. Foot health needs to be "when I have a problem" Diet again, you might want to share when you've had a specific problem. Diabetes doesn't fit a regular timetable so weekly, monthly doesn't always work. Sometimes we need help between diabetes specialist appointments. Pregnancy/contraception needs an N/A option. I get SO fed up of being asked about smoking and alcohol please do not add it here too.” – PWDT1</p>
Share when necessary	7	0	
Share when there is an update	1	0	
Information should always be available	1	0	
6-monthly	3	0	
Quarterly	1	0	
Before appointments (or if not annually)	1	0	
Willingness to share:			
Not willing	2	0	<p>“I want to keep my information private - I would only want to share information in the rare event that I had a problem that I could not fix any other way. I do not want to feel that I am being watched over.” – PWDT1</p> <p>“Some of these questions were not a simple yes and no for me so a maybe option and a comment as why would have been good especially around Hypos and why I wouldn't want that sharing etc as I feel that's really important especially for younger people” – PWDT1</p> <p>“I think the more holistic information the practitioner has the better appointment I would get and the daily information would give</p>
Willing to share	6	0	
Need flexibility about what to share (not all information applicable to everyone)	4	0	
Automatically generated data should be available (e.g. from CGM)	1	0	
Share appropriate amount	1	0	

			<p>indications of possible events and allow tracking to be managed better by health care professionals.” - PWDT2</p> <p>“I’m happy for virtually all my information to be shared with people who can help me to improve my self-care and to aid research. I am not happy to be lectured or hectored my clinicians which sadly can often still be the case as a Type 1 Diabetic” – PWDT1</p> <p>“Quality data can help teams better understand care but too much data becomes meaningless” – PWDT1</p>
Ability to capture and share information:			<p>“I currently have access to systems such as Freestyle Libre which allows me to share my diabetes related information and results with my diabetes team via internet. I have great back up from my Diabetes Specialist Nurse and I have access to the team 7 days a week.” - PWDT1</p>
Equipment not available for people with type 2	2	0	
Already capturing and sharing	2	0	
No contact from HCPs for sharing	1	0	
Review meetings:			<p>“We no longer have holistic reviews with a consultant. Our care seems to have been passed over to GP practices. Digital consultations maybe convenient for health professionals but this means I do not receive holistic accurate assessments so diagnoses also may not be accurate.” – PWDT2</p>
Lack of holistic meetings	2	0	
Can raise concerns, fears	1	0	
Prefer to discuss with hospital team rather than GP practice	1	0	
Sharing data could trigger an earlier appointment or feedback outside the review cycle	2	0	
Other information:			<p>“Menopause - this part of reproductive health is completely off everyone in healthcare's radar” – PWDT1</p> <p>“People with diabetes are carers as well as in some cases, cared for. I think this is important to be aware of.” - PWD</p>
Kidney and eye monitoring	1	0	
Menopause	1	0	
Blood test results	1	0	
DIY looping	1	0	
Carer status	1	0	
Other comments			<p>“Need to be careful with diet/ exercise as not always a healthy thing to put focus on. I think eating a healthy balanced diet is important. But shouldn't be too much focus on that with kids as they want to be same as their</p>
Diet and exercise	0	1	

			peers and to avoid an unhealthy obsession with food especially having coeliac to contend with too.” - Parent
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* Responses for comments were qualitative. As such, figures above show the number of times a given theme was mentioned but are not generalisable or necessarily indicative of an overall preference or lack of the same. Some responses generated multiple themes.

4.2 On sharing other information with HCPs

People with diabetes and their carers or parents were asked variations of the following question:

‘Is there other information you would like to share with healthcare professionals? E.g. topics to discuss at the next review meeting or concerning measurements taken at home.’

AND

‘How would you like to share this information?’

A summary of key themes identified for the first and second questions above are presented in tables 8 and 9 respectively.

Key points

- The most highly cited themes were measurements taken at home (n=6) and information about comorbidities (n=5).
- Other cited themes included topics concerning the PWD (n=4), menstrual cycle/ menopause (n=4), mental health issues (n=4), and dietary information (n=4).

Table 8 – Thematic analysis: Other information to share with HCPs

Is there any other information you would like to share with your healthcare professional?			
Theme	Person (n)	Parent (n)	Key quote(s)
Issue for review:			<p>“I’d like to inform doctor of topics of concern before review.” – PWD T1</p> <p>“I would like to be able to send questions in advance so that [the healthcare professional] can prepare.” – PWD T1</p> <p>“An assessment of how [HCPs] are performing and meeting my needs. What can they reflect on and how can they improve.” – PWD T1</p> <p>“Members of the team that my child engages most with, and why.” – PWD T1 (Parent)</p>
Topics concerning the PWD	4	0	
Medications review	2	0	
Measurements taken at home *	6	0	
Questions sent in advance	2	0	
Feedback for HCP	1	1	
Personalised goals	0	1	
Factors affecting person and their diabetes:			<p>“At the hospital where the diabetes clinic is based, it seems that they have no record of other issues. This can have a major impact on discussion & them knowing would save a lot of time. Information should be shared whatever your other health issues are or have been.” – PWD T1</p> <p>“[I want to share] how other health conditions are affecting my diabetes.” – PWD T1</p>
Comorbidities affecting the person’s diabetes**	5	0	
Menstrual cycle/ menopause	4	0	
Sexual health e.g. lack of sex drive, erectile dysfunction	3	0	
Mental health issues	4	0	

Significant life events	1	1	<p>“Menstrual cycle especially linked to menopause, or for younger people if cycle is impacting blood sugar.” – PWD T1</p> <p>“Sexual function should be a routine question.” – PWD T1</p> <p>“How they are coping with big changes moving to secondary school etc. We always talk about big changes as [these] could affect [blood glucose] control temporarily. Even if normally have good management.” – PWD T1 (Parent)</p>
Health and lifestyle management:			<p>“I want to be able to discuss DIY Looping fully and openly and usefully with my team.” – PWD T1</p>
Dietary information	4	0	
Exercise levels	1	0	
Pain management	1	0	
Sleep hygiene	1	0	
Insulin management	3	0	
Stress management	2	0	
Growing older with diabetes	2	0	

* Examples given of measurements taken at home were blood pressure, height, weight, waist circumference, assessments of mood and sugar levels.

** Other health conditions mentioned included hearing issues (n=1), coeliac disease (n=1), hypothyroidism (n=1), and diabetic eye disease (n=2) and recurrent infections (n=1).

Responses for analysis were qualitative. As such, figures above show the number of times a given theme was mentioned but are not generalisable or necessarily indicative of an overall preference or lack of the same. Some responses generated multiple themes.

Key points

- The most highly cited themes were by verbal appointment or review (n=25) (e.g., in person (n=17) or by telephone (n=7)) or digitally (n=37) (e.g., via an app/ web portal (n=16), by email (n=14) or via an online form or survey (n=7)).
- Other cited themes included examples of when to share and who with.

Table 9 – Thematic analysis: How to share information with HCPs

How would you like to share this information?			
Theme	Person (n)	Parent (n)	Key quote(s)
By verbal appointment or review:	23	2	<p>“[Via] an email for concerns, followed by receiving [a] phone call or face to face [contact].” – PWD T1</p> <p>“I would like to discuss the matter in a face to face meeting whenever this is required.” – PWD T2</p>
In-person/ face-to-face	15	2	
By telephone	7	0	
By remote consultation	2	0	
Electronically/ digitally:	37	2	<p>“Electronically, preferably [information shared would] pull through to a dashboard that [clinicians] are able to log in and view should they so wish. Critically though, I would like to retain control and</p>
Via an app or web portal	16	0	
By email	14	0	

Via online form or survey	5	2	responsibility of my own condition and would not expect them to monitor remotely." – PWD T1 "If I was concerned it would be useful to raise a query on the NHS App." – PWD T2 "An app, ...the diabetic midwives can access this information as soon as I have taken the reading. It would be nice to be able to relay more to them via such a simple method." – PWD (Gestational)
With the following:			"I would be happy for my medical information to be shared amongst all clinical/medical staff and those within emergency services, via access to a centralised medical records system, accessible throughout the UK." – PWD T1 "By a face to face discussion or phone call or peer support group." – PWD T2 "Anyone who is interested, research, mentoring. To help others with chronic illnesses." – PWD T1
GP or practice nurse	2	0	
Peer support group	2	0	
Symptoms diary	1	0	
The wider health service	3	0	
School nurse/ representative	0	1	
Diabetes specialist nurse	1	1	
At the following times:			"Automatically via a single open interop[erable] format so that neither I nor the HCP has to worry about dealing with multiple platforms for the data." – PWD T1 "If I could share my agendas before a consultation, it would help the doctor and the nurse to prepare." – PWD T2
Before appointments	3	1	
Periodically as required	3	2	
Automatically/ in real-time	3	0	

Responses for analysis were qualitative. As such, figures above show the number of times a given theme was mentioned but are not generalisable or necessarily indicative of an overall preference or lack of the same. Some responses generated multiple themes.

4.3 On what to record in a diabetes care plan

People with diabetes and their carers or parents were asked variations of the following question:

'Please select the information that should be captured in a diabetes care plan. Any comments?'

Responses about which information should be captured in a diabetes care plan were selected from a pick list of 11 information categories (see table 10).

Key points

- People with diabetes and their carers generally supported the need for capturing this information in a diabetes care plan. At least 60% of responses in each group (PWDT1, PWDT2, parent of T1) supported the inclusion of at least 9 out of the 11 information categories.
- People with type 2 diabetes were least likely to want to capture information about additional supporting/ contingency plans (47.2%, n=17).
- People with type 1 diabetes were least likely to want to capture information about confidence in achieving goals (53.3%, n=48).
- Parents of children with type 1 supported the inclusion of each of the 11 categories with at least 60% of responses.

Key quote(s)

In the comments provided respondents generally indicated support for the concept of care plans. Some comments expressed scepticism or queried how it would work in practice as

well as the use of the term 'care and support plan, which it was felt had negative connotations of weakness and vulnerability.

- “It would be nice to have my healthcare professional know this so they can best support me with my health and to make sure that diabetes doesn't stop me achieving my goals.” – **PWD T1**
- “Living with an unpredictable condition like MS means I prefer not to make long term plans & goals, as everything can change instantly if I have a relapse. I find it depressing not to achieve goals so tend to make very vague & flexible ones with no specific end date.” – **PWD T1**
- “This is all well and good, but I do not think for an instant that the professional will be able to consider all these nuances. I'll be grateful just to be kept in the loop occasionally.” – **PWD T2**
- “Ideally any care plan would be reviewed, amended or updated frequently.” – **PWD T1**

Table 10 – Information to capture in a diabetes care plan

Which information should be captured in your/your child's care plan?			
Information	PWDT2 % Yes Total n = 36	PWDT1 or other % Yes Total n = 90	Parents of T1 % Yes Total n = 8
Your identifying information: For example, your name, date of birth and address.	72.22	81.11	100.00
Your GP details: This includes your GP's name and practice details.	72.22	81.11	100.00
Important information about you: The information about you that you want people caring for and supporting you to know including your needs, preferences, concerns and wishes	61.11	82.22	100.00
Your strengths: That may help you to achieve your health and wellbeing goals.	58.33	61.11	87.50
Your needs, concerns or problems: That are relevant to your ability to achieve your health and wellbeing goals.	63.89	73.33	87.50
Your goals and hopes: That relate to your future health and wellbeing.	69.44	70.00	75.00
Actions you want to carry out to achieve the goals	63.89	63.33	62.50
Any obstacles or barriers to achieving your goals	63.89	65.56	75.00
Your confidence in achieving them	61.11	53.33	62.50
Planned review date and responsibilities: For yourself and your healthcare professional.	72.22	80.00	62.50
Additional supporting and contingency plans: (e.g. school insulin pump plan or hypoglycaemia action plan)	47.22	66.67	87.50

4.4 On the information needed to develop and agree a diabetes care plan

People with diabetes and their carers or parents were asked variations of the following question:

‘To develop and agree a care plan what information from the healthcare record would healthcare professionals need to have available?’

Responses of ‘never’, ‘sometimes’, ‘nearly always’ were selected against a list of 9 information categories (see table 11).

Key points

- There was broad agreement across responses that this was the key information required for care planning with ‘nearly always’ mostly for almost all categories by each group (PWDT1, PWDT1, parents).
- Significant exceptions were that most people with type 2 diabetes felt that pregnancy status (72.7%, n= 16) was ‘never’ required. Possible confounding factors include age, sex, and fertility status (which were not collected in this survey) as well as a low response rate that might explain this result.

Key quote(s)

In the comments provided respondents (with some exceptions) generally indicated support for care planning, with the caveat that information requirements may differ depending on the individual PWD and circumstances.

- “Information is key - if all clinicians have access to ALL the information at any time then they can see the whole ‘person’ picture not just snapshots relating to a speciality or single appointment” – **PWD T1**
- “[The information is ok] people who want a care plan, personally I wouldn't.” – **PWD T1**
- “If the care plan is drawn up to cover a specific incident, such as following a surgical procedure, I would say that historical information could be limited to more recent issues. But if the care plan is a general plan for long term care, clearly all of the patient's historic information should be available in it” – **PWD T1**

Table 11 – Information needed to develop a diabetes care plan

To develop and agree a care plan what information from your/your child’s record would you/your child and your healthcare professional need to have available?					
Information		Never %	Sometimes %	Nearly always %	Total n
Demographics and contacts	T2	11.54	23.08	65.38	26
	T1	10.26	32.05	57.69	78
	P	0.00	0.00	100.00	8
Legal information	T2	22.22	40.74	37.04	27
	T1	17.95	38.46	43.59	78
	P	0.00	25.00	75.00	8

Social context (for example smoking, alcohol, social circumstances, occupation, driving status)	T2	15.38	42.31	42.31	26
	T1	8.97	35.90	55.13	78
	P	Not asked	Not asked	Not asked	Not asked
Pregnancy status (for example pregnant or trying for a baby)	T2	72.73	9.09	18.18	22
	T1	36.84	21.05	42.11	76
	P	Not asked	Not asked	Not asked	Not asked
Safeguarding and risks	T2	41.67	20.83	37.50	24
	T1	19.74	25.00	55.26	76
	P	0.00	0.00	100.00	8
Medications and allergies	T2	18.52	7.41	74.07	27
	T1	2.63	7.89	89.47	76
	P	0.00	0.00	100.00	8
Encounters: referrals (for example for structured education)	T2	18.52	14.81	66.67	27
	T1	3.90	29.87	66.23	77
	P	0.00	12.50	87.50	8
Admission details	T2	15.38	11.54	73.08	26
	T1	3.85	20.51	75.64	78
	P	0.00	12.50	87.50	8
Discharge details	T2	11.11	7.41	81.48	27
	T1	3.85	17.95	78.21	78
	P	0.00	0.00	100.00	8
Investigation results (for example blood tests such as your haemoglobin A1c levels or urine tests related to diabetes)	T2	7.41	14.81	77.78	27
	T1	2.60	7.79	89.61	77
	P	0.00	0.00	100.00	8
Examination findings (for example foot check or eye screening results)	T2	7.41	11.11	81.48	27
	T1	2.56	8.97	88.46	78
	P	25.00	12.50	62.50	8
Measurements (for example blood pressure, heart rate or sugar levels)	T2	7.41	14.81	77.78	27
	T1	5.13	11.54	83.33	78
	P	0.00	0.00	100.00	8
Assessments (for example questionnaires about diabetes or general health and wellbeing)	T2	7.41	18.52	74.07	27
	T1	3.85	25.64	70.51	78
	P	0.00	37.50	62.50	8
Problem list (such as a diagnosis, abnormal test result, concerning symptom, or other health related issue)	T2	18.52	7.41	74.07	27
	T1	2.56	16.67	80.77	78
	P	0.00	12.50	87.50	8
	T2	14.81	7.41	77.78	27

Procedures (operations or other therapies related to diabetes)	T1	5.13	14.10	80.77	78
	P	0.00	12.50	87.50	8
Other plans and actions (agreed action for the healthcare professional or person or their carer to take)	T2	11.11	14.81	74.07	27
	T1	2.60	11.69	85.71	77
	P	0.00	12.50	87.50	8

T2 = PWD with type 2 diabetes and carers of people with type 2 diabetes responding from the perspective of the people they care for. **T1** = PWD with type 1 diabetes and carers of people with type 1 diabetes responding from the perspective of the people they care for. **P** = parents of children with type 1 diabetes. Values in **bold** are the most selected frequencies.

4.5 On recording structured education

People with diabetes, their carers or parents, healthcare professionals, systems suppliers and others were asked variations of the following question:

‘What information, if any, should be recorded about the outcomes of the structured education programmes a person with diabetes has attended?’

Thematic analysis of responses is summarised in table 12.

Key points

- The most highly cited themes were around programme details including name of programme (n=92), record of attendance/ date (n=75), record of completion/ date (n=41). Several HCP responses indicated a need to record the offer/ date (n=8).
- Both PWD (n=9) and HCPs (n=6) cited the need to record a person’s view of benefit as well as outcomes including a follow-up plan (n=5 and 14 respectively).
- Other themes commonly cited by HCPs included a person’s understanding/ competency and confidence (n=7) following structured education. A PWD’s engagement/ motivation (n=8) and the need for extra help or a refresher course (n=9) were also cited by HCPs.

Key quote(s)

- “What are the outcomes of education? These have never been satisfactorily researched and defined. HbA1c - no. Self-management skills - possibly, but is it more about what they do rather than about what they know? Satisfaction - no. QOL scores - we measure them, but not sure of relevance in longer-term.” – **Healthcare professional**

Table 12 – Thematic analysis: Recording structured education

What information should be recorded about the outcomes of structured education programmes?					
Theme	Person (n)	Parent (n)	HCP (n)	Sys. (n)	Other (n)
Programme details:					
Name of programme	22	2	58	2	8
Record of attendance/ date	18	2	47	2	5
Record of completion/ date	9	0	23	3	6
Record of referral/ date	0	0	3	0	0

Record of offer/ date	1	0	8	0	1
Person details:					
Person's view of benefit	9	0	6	0	3
Understanding/ competency	3	1	7	0	2
Confidence	1	0	7	0	2
Engagement/ motivation	0	0	8	0	0
Refresher/ extra help req.	0	0	9	0	0
Outcomes:					
PROMS	0	0	2	2	0
Goals	0	0	8	0	1
Clinical outcomes e.g., HbA1c	2	0	3	2	2
Follow-up and plan	5	0	14	0	1

Responses for analysis were qualitative. As such, figures above show the number of times a given theme was mentioned but are not generalisable or necessarily indicative of an overall preference or lack of the same. Some responses generated multiple themes.

4.6 On whether timely sharing of data between systems would improve diabetes care

People with diabetes, their carers or parents, healthcare professionals, systems suppliers and others were asked the following question:

'Would sharing information digitally between computer systems so professionals and people have real (near real) time information improve care? If so, how?'

Thematic analysis of responses is summarised in table 13.

Key points

- Most respondents (95.0%, n=228) answered 'Yes'.
- The most highly cited themes (see table 13) are supported in the following general statements:
 - Use of real time data in diabetes care would...
 - *Ensure that all HCPs involved in the care of a PWD have easy access to all the data they need to see, that this represents a complete and holistic view of the person and supports joined up/ continuity of care.*
 - *Ensure that HCPs caring for a PWD have key information to hand to improve clinical decision making and consultations.*
 - *Ensure that records are kept accurate/ up to date.*
 - *Save HCPs time, avoid delays, and provide timely access to patient data*
 - Help to avoid PWD having to repeat their story to multiple HCPs more than once.
 - Help to avoid duplication of tests, interventions, and clinical effort.

Key quote(s)

- “Looping information is very rich and having access to view that at the time of an issue and/or clinic appointment would help to untangle the issue and identify areas of concern/good to then action/appreciate in a timely way. It would also help to ensure current information is provided to work from that fits current context.” – **PWDT1**
- “Frustration arises when constantly having to repeat oneself in order to give up to date info. Notes should always be referred to when consulting with a patient, so limited consultation time can be used constructively rather than going over old ground.” – **PWDT1**
- “Information accessible in one place reduces work trying to collate as well as interpret - with info collated we only need to interpret and not waste time trying to pull together all the sources. Also reduces risk of not having important info that could modify care pathway and can enable efficiencies in targeting healthcare and in preventing untoward admission/ attendances/ improving patient QOL/ and reduced costs.” - **Endocrinologist**

Table 13 – Thematic analysis: Real time data sharing

Would sharing information between systems in (near) real time improve diabetes care?					
Theme	Person (n)	Parent (n)	HCP (n)	Sys. (n)	Other (n)
Respondents answering yes or no:					
Yes	95	8	102	7	16
No	9	0	3	0	0
Most highly cited themes in comments (Yes, to....)					
Ensure that all HCPs involved in the care of a PWD have easy access to all the data they need to see, that this represents a complete and holistic view of the person, and supports joined up/ continuity of care	26	2	23	1	2
Ensure that HCPs caring for a PWD have key information to hand to improve clinical decision making and consultations	10	0	11	1	0
Keep record accurate/ up to date	15	0	14	1	1
Avoid duplication of tests, interventions, and clinical effort	3	0	11	0	1
Save HCP time, avoid delays, and timely access to patient data	13	1	12	0	3
Avoid PWD having to repeat their story to multiple HCPs	9	2	0	0	0
Share data with HCPs caring for the PWD and working in external organisations / in the community	0	0	9	0	1

Improve safety and avoid risks and errors associated with incomplete or fragmented record where there may be multiple/ conflicting sources of the truth e.g. the medicines a person is taking	4	0	7	0	1
Yes, with the caveat that...					
HCPs need time available to review extra information	4	0	2	0	0
The information is correct	1	0	0	0	0
That patient confidentiality is preserved	0	0	1	0	1
PWD has access to their record	1	0	1	0	3
Security safeguards are in place	2	0	0	0	0
Other themes (Yes, to...)					
Generate an actionable clinical picture	2	0	0	1	0
Support PWD autonomy and empowerment	0	0	3	0	1
Improve blood glucose control with access to real-time data	4	1	2	0	0
Improve healthcare efficiency and use of resources	2	1	2	0	1
Identify trends and patterns	3	0	1	1	0

Responses for analysis were qualitative. As such, figures above show the number of times a given theme was mentioned but are not generalisable or necessarily indicative of an overall preference or lack of the same. Some responses generated multiple themes.

4.7 On other issues that would affect the difficulty of sharing information

People with diabetes, their carers or parents, healthcare professionals, systems suppliers and others were asked variations of the following question:

‘Are there any other issues that would make sharing information on diabetes care easier or harder?’

Thematic analysis of responses is summarised in table 14.

Key points

- The most highly cited themes indicated that information sharing would become easier with improved interoperability (n= 27) and digital access (n=18), and reduced information governance barriers (n=19).
- People with diabetes emphasised that improved non-specialist understanding of diabetes management and devices was needed (n=8).

Key quote(s)

- “Industry providers are not making their systems open. They are not sharing patients BG data. This leads to HCP's having to use multiple different systems to view patients' data. All systems can easily speak to each other, there needs to be a framework that makes this happen.” – **System supplier**

- “The fire walls set up to protect the IT systems in the hospital often make it difficult to use these platforms e.g. when they are upgraded or new software is being used by pts. It can take a lot of time and communication with IT and IG to get these things working and approved. I don't see an easy solution for this, other than one central way to view the data (like Diasend started out).” - **Dietician**
- “[It would be made easier with] one platform for all data - interoperability is key here!! If I am using a CGM (Libre 2 for example) I don't want to have to copy this data across to an app that will support me with calculating my dosage requirements, it needs to pull the data across.” – **PWDT1**

Table 14 – Thematic analysis: Issues affecting sharing of information

Are there any other issues that would make sharing information on diabetes care easier or harder?					
Theme	Person (n)	Parent (n)	HCP (n)	Sys. (n)	Other (n)
Healthcare / HCP issues:					
Interoperable IT systems	8	0	14	3	2
Standardised digital records	0	0	7	0	2
Digital access/ infrastructure	7	1	9	0	1
Data security issues	1	0	0	0	0
Data volume from devices	0	1	1	0	0
Non-specialist understanding of diabetes management/ devices	8	1	0	0	0
Information governance barriers	5	0	11	0	3
Barriers to sharing across local and national borders	1	0	1	0	0
Resources and funding	0	0	2	0	0
HCP ability to read/ write to system and ensure up-to-date and accurate records	0	0	0	0	1
Person related issues:					
Burden of condition and management on PWD	2	0	0	0	0
PWD device understanding	1	0	2	0	0
PWD self-custody/ access to their personal health data	1	0	1	0	0
PWD peer support/ information exchange	1	0	0	0	0
Written information shared with PWD	2	0	0	0	0

Responses for analysis were qualitative. As such, figures above show the number of times a given theme was mentioned but are not generalisable or necessarily indicative of an overall preference or lack of the same. Some responses generated multiple themes

4.8 On population health management

People with diabetes, their carers or parents, healthcare professionals, systems suppliers and others were asked the following question:

‘To improve local services for people with diabetes, the NHS needs to analyse data from local people who have this condition. Would you support sharing information for this use?’

Thematic analysis of responses is summarised in table 15.

Key points

- Most respondents (91.2%, n=218) answered ‘Yes’.
- The most highly cited themes in the comments (particularly amongst PWD and HCPs) were that people supported interventions to help other people with diabetes (n=23), to improve knowledge, services, and care planning for local PWD (n=43), and to create locally targeted interventions (n=20). Several people stated that the more data collected the better for diabetes care (n=13).
- Both PWDs and HCPs caveated their support by emphasising the of importance of the data being collected anonymously, with appropriate safeguards and with the consent of the PWD (n=15).

Key quote(s)

- “However, the need to collect, use and retain this data locally MUST be carefully considered and evaluated. A full written assessment including community consultation is required to justify the collection and retention of any personal or anonymous data. Otherwise, data is collected 'because we think we need it' rather than for a defined and time limited purpose.” – **Patient body representative**
- “It's more of a maybe, it depends exactly what data would be shared, who had access to it, how the data is being used and what the retention policy is.” – **PWDT1**
- “[B]ecause there may be local trends which could be economically addressed i.e., specialised clinics or education programs. data should be analysed on a regular basis in order to update trends.” – **PWDT2**
- “Given the consent (and full control) of people with diabetes diverse stakeholders could benefit from the access to data: researchers and companies to gather insights for research and improve drugs, medical devices and digital health solutions; developing, testing and validating algorithm to improve health care services and products; regulators to monitor safety; authorities to access RWD for assessment & reimbursement purposes; HCPs to inform their decision making and last but not least: patients to empower them for better self-management, increase their health literacy and share their preferences and needs.” – **Systems supplier**
- “It's important to understand local trends as well as national trends so we can adapt the service to support the requirements. For example, staffing levels.” – **Podiatrist**

Table 15 – Thematic analysis: Support for population health management

To improve local services for people with diabetes, the NHS needs to analyse data from local people who have this condition. Would you support sharing information for this use?					
Theme	Person (n)	Parent (n)	HCP (n)	Sys. (n)	Other (n)

Respondents answering yes or no:					
Yes	97	7	93	5	16
No	9	1	9 *	2	0
Most highly cited themes in comments (Yes, to...):					
Help other people with diabetes	22	0	1	0	0
Improve knowledge, services, and care planning for local PWD	24	1	15	2	1
Capture data representative of the local population with type 1 or type 2 diabetes and create targeted interventions	15	0	5	0	0
Collect as much data as possible – the more data the better to identify health trends and improve diabetes care	7	0	5	0	1
Other themes (Yes, to...):					
Help me manage my diabetes	2	0	0	0	0
Reduce regional inequalities in diabetes care	0	0	1	0	1
Empower patients	0	0	1	0	0
Yes, with the caveat that...					
The data is collected with the consent of the PWD, is anonymous, and had appropriate safeguards	6	0	7	0	2

*Most professionals who answered 'No' to this question stated that they could not answer without having had lived experience of diabetes.

Responses for analysis were qualitative. As such, figures above show the number of times a given theme was mentioned but are not generalisable or necessarily indicative of an overall preference or lack of the same. Some responses generated multiple themes

4.9 On where information sharing breaks down

People with diabetes, their carers or parents, healthcare professionals, systems suppliers and others were asked the following question:

'Tell us about where information sharing breaks down e.g., between the podiatrist and GP, or district nurse and hospital team.'

Thematic analysis of responses is summarised in table 16.

Key points

- The most highly cited themes in the comments indicated that information sharing breaks down between the GP and hospital teams (n=65), between hospital teams within a trust (n=9), between hospital trusts (n=10), between the hospital teams and community care (n=11), between diabetic eye screening services and hospital teams (n=11) and between the podiatrist in the community and others (n=18). Several respondents said that information sharing breakdown was systemwide (n=21) although some PWDs said they had no experience of this (n=10).

- It was mostly HCPs that emphasised issues around key data being held in siloes (n=19), delays in receiving discharge summaries from hospitals (n=7), and the use of breakdown in sharing information where paper records or letters are used (n=11).

Key quote(s)

- “[Information breaks down] between (particularly private) podiatrist and GP, between hospital/ hospital lab and GP, between eye screening and GP, between hospital lab and hospital consultant, between CGM manufacturers and any outside systems. We have data coming out of lab systems, locked up in PDF documents, sent as documents, but never coded, meaning it can't be meaningfully used for analysis and support.” – **System supplier**

Table 16 – Thematic analysis: Where information sharing breaks down

Tell us about where information sharing breaks down.					
Theme	Person (n)	Parent (n)	HCP (n)	Sys. (n)	Other (n)
Identified information flows where information sharing breaks down:					
GP ↔ Hospital teams	24	3	32	3	3
GP ↔ PWD	2	0	1	0	0
PWD ↔ Hospital teams	1	0	2	0	0
Between hospital teams	4	0	3	1	1
Between hospital trusts	5	0	4	0	0
GP ↔ Community Care	0	0	5	0	1
GP ↔ Pharmacy (comm.)	2	0	0	0	1
GP ↔ District nurse	1	0	1	0	2
GP ↔ Dietician	0	0	1	0	0
Hospital ↔ Community care	0	0	9	0	2
Hospital ↔ District nurse	0	0	1	0	0
PWD ↔ Pharmacy (comm.)	1	0	1	0	0
Eye screening ↔ GP	1	0	0	1	1
Eye screening ↔ Hospital	2	0	8	0	1
Podiatrist ↔ Others	2	0	13	1	2
Mental health ↔ Others	0	0	2	0	1
Private healthcare ↔ Others	2	0	0	0	1
Device data → Other systems	0	0	0	0	1
CCG ↔ CCG	1	0	0	0	0
Country ↔ Country	1	0	0	0	0
Systemwide/ ubiquitous	16	0	2	1	2
Breakdown not experienced	10	0	0	0	0
Transition * or transfer of care	0	0	2	0	1

Other themes:					
Available records not accessed	2	0	0	0	0
Wrong data or sharing delayed	2	0	0	0	0
Wrong data format	0	0	0	1	0
Test/ path results not accessible	4	0	1	0	0
Key data held in siloes	1	0	13	2	3
Discharge summary delayed	0	0	5	0	2
Non-digital paper records/ letters	0	0	11	0	0
Overwhelming volume of data	0	0	1	0	0
Emergency callouts not shared	0	0	1	0	0

Responses for analysis were qualitative. As such, figures above show the number of times a given theme was mentioned but are not generalisable or necessarily indicative of an overall preference or lack of the same. Some responses generated multiple themes

4.10 On where HCPs are unable to access information they need to see

People with diabetes, their carers or parents, healthcare professionals, systems suppliers and others were asked variations of the following question:

‘What information about people with diabetes are healthcare professionals unable to access that they need to see?’

Thematic analysis of responses is summarised in table 17.

Key points

- The most highly cited themes in the comments included examples of where records are held outside of an HCP’s organisation (n=19), access to test results including images, scans, and reports (n=20), medications taken including changes (n=11), diabetic eye screening results including images (n=13), data from devices including CGM and insulin pumps (n=14) as well as several other elements common to patient health records e.g. observations, allergies etc.(n=21).
- Several HCPs indicated difficulty accessing details and outcomes from PWD’s hospital inpatient stay (n=8), details of treatment plans made by other HCPs (n=7), details of community podiatry notes or foot checks (n=7).

Key quote(s)

- “Inpatient notes. These are handwritten on wards and are impossible for community members to view. These notes are important for context of the case. We rely on discharge summaries which we have to log in to a separate system to view. Discharge summaries are often medically focused, but our information is mostly led by surgical input.” – **Podiatrist**

Table 17 – Thematic analysis: Information HCPs need to see but are unable to access

What information are healthcare professionals unable to access that they need to see?					
Theme	Person (n)	Parent (n)	HCP (n)	Sys. (n)	Other (n)

Most highly cited responses:					
Records held outside of their organisation, trust, or CCG etc. including mental health, optician, & maternity records	12	1	3	0	3
Test results including images, scans, and reports etc.	7	0	9	1	3
Medications taken including reasons for changes	1	0	9	0	1
Diabetic eye screening results including images	3	0	7	2	1
Details and outcomes from PWD's hospital inpatient stay	0	0	7	0	1
Details of treatment plans made by other HCPs	1	0	6	0	0
Podiatry notes or foot checks/ screening in the community	1	0	5	0	1
Other elements common to patient records e.g., observations, allergies, care plans, past medical history etc.	10	0	11	0	0
Other themes:					
Exercise activity (e.g., steps)	2	1	0	0	0
Data from devices including CGM and insulin pumps etc.	3	0	6	5	0
Community pharmacy consultation details or prescription collected notification	0	0	3	0	0
Out of hours records	0	1	0	0	0
Details of adverse life events	1	0	0	0	0
Details of carbohydrate and food intake	1	0	0	0	0
Details of what why an action was taken or what PWD was told by another HCP	0	0	2	0	0

Responses for analysis were qualitative. As such, figures above show the number of times a given theme was mentioned but are not generalisable or necessarily indicative of an overall preference or lack of the same. Some responses generated multiple themes

4.11 On information recorded at home that HCPs need to see and when

Healthcare professionals, systems suppliers and others were asked variations of the following question:

'Which of the following information that could be recorded by a person with diabetes at home would healthcare professionals use in caring for them and when would it be needed?'

Responses of 'never', 'at scheduled appointments', 'in between appointments', 'after a significant event', 'other', 'I don't know' were selected against a list of up to 17 information

categories depending on whether a respondent was an HCP, system supplier, or other (see table 18).

Key points

- There was broad agreement across responses (HCPs, suppliers, others) supporting the need for HCP access to the listed categories. The most highly selected response for each category tested was generally that information should be shared at scheduled appointments.
- Overall HCPs supported this for all 17 categories (100%, n=17) whereas systems suppliers indicated that information should be shared in between appointments for blood sugar (85.7%, n=6), episodes of hypoglycaemia (100%, n=7) and insulin dosing (85.7%, n=6). These findings may reflect that these are examples of the data shared in real time/ near real time from diabetes devices (such as RT-CGM e.g., DEXCOM G6, IS-CGM e.g., Freestyle Libre, connected insulin pens, and pumps etc) that are familiar to systems suppliers. Clinicians have also shared with us their concerns around the uncertainties and lack of clear guidance about what their clinical responsibility is to action continuous streams of live device data or alerts (e.g., hypoglycaemia) outside of scheduled clinic appointments.
- Systems suppliers were equivocal about whether about me information, measurements or self-assessments at home should be shared 'at scheduled appointments' (42.9%, n=3) versus 'in between appointments' (42.9%, n=3) however it is difficult to draw reliable conclusions about system supplier preferences due to a very small sample size (n=7).
- A few categories were identified where a minority of HCPs reported they never needed to see information including about sleep (30.9%, n= 34), self-assessments done at home by the PWD (0.7%, n = 23), and family planning/ pregnancy (17.4%, n=19).
- Some respondents felt the options for selection in this question were too restrictive – many professionals often wanted to select multiple options but were unable to do so.

Key quote(s)

Most comments suggested that anyone involved in the care of the PWD (and the person themselves) would require access to the information. The specific roles mentioned in the comments are listed in table 19 below.

- “The survey doesn't give you the option for multiple responses - access to the info at all scheduled appointments is needed but also on an ad hoc bases between appointments or if a significant event happens. Person with diabetes, Diab nurses, dietitians, primary / secondary care docs / practise nurse.” – HCP

Table 18 – Information recorded at home that HCPs need to see and when

<p>Which of the following information that could be recorded by a person with diabetes at home would an HCP use in caring for them and when would you need it?</p>

Information		Never %	At scheduled appointments %	In between appointments %	After a significant event e.g. severe hypoglycaemic event	Other %	I don't know %	Total n
Blood sugar	HCP	0.89	60.71	22.32	6.25	9.82	N/A	112
	S	0	14.29	85.71	N/A	N/A	0	7
	O	0	31.25	62.5	N/A	N/A	6.25	16
Episodes of hypoglycaemia	HCP	1.80	54.05	17.12	18.02	9.01	N/A	111
	S	0	0	100	N/A	N/A	0	7
	O	0	31.25	62.5	N/A	N/A	6.25	16
Medications	HCP	1.80	77.48	9.01	4.50	7.21	N/A	111
	S	0	85.71	14.29	N/A	N/A	0	7
	O	0	37.5	43.75	N/A	N/A	6.25	16
Insulin	HCP	3.60	62.16	20.72	3.60	9.91	N/A	111
	S	0	14.29	85.71	N/A	N/A	0	7
	O	0	43.75	50	N/A	N/A	6.25	16
Physical activity	HCP	8.04	75.00	8.04	0.89	8.04	N/A	112
	S	0	71.43	28.57	N/A	N/A	0	7
	O	0	68.75	18.75	N/A	N/A	12.5	16
Sleep	HCP	30.91	45.45	3.64	6.36	13.64	N/A	110
	S	0	71.43	14.29	N/A	N/A	14.29	7
	O	6.25	56.25	18.75	N/A	N/A	18.75	16
Diet	HCP	7.21	66.67	10.81	2.70	12.61	N/A	111
	S	0	73.33	28.57	N/A	N/A	0	7
	O	0	68.75	13.33	N/A	N/A	13.33	15
Mental health	HCP	3.57	75.00	8.93	1.79	10.71	N/A	112
	S	0	16.67	33.33	N/A	N/A	50	6
	O	6.25	56.25	25	N/A	N/A	12.5	16
Self-assessments at home	HCP	20.72	56.76	12.61	1.80	8.11	N/A	111
	S	0	42.86	42.86	N/A	N/A	14.29	7
	O	6.25	50	31.25	N/A	N/A	12.5	16
Smoking status	HCP	2.70	89.19	0.90	1.80	5.41	N/A	111
	S	0	85.71	14.29	N/A	N/A	0	7
	O	0	75	12.5	N/A	N/A	12.5	16
Alcohol intake	HCP	0.89	87.50	1.79	2.68	7.14	N/A	112

	S	0	85.71	14.29	N/A	N/A	0	7
	O	0	75	12.5	N/A	N/A	12.5	16
Family planning / pregnancy	HCP	17.43	57.80	11.01	2.75	11.01	N/A	109
	S	0	71.43	28.57	N/A	N/A	0	7
	O	0	62.5	18.75	N/A	N/A	18.75	16
Measurements at home	HCP	5.50	68.81	11.93	3.67	10.09	N/A	109
	S	0	42.86	42.86	N/A	N/A	14.29	7
	O	0	56.25	31.25	N/A	N/A	12.5	16
Foot checks	HCP	8.04	72.32	13.39	0.00	6.25	N/A	112
	S	N/A	N/A	N/A	N/A	N/A	N/A	N/A
	O	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Goal setting and progress against these	HCP	8.93	72.32	9.82	0.89	8.04	N/A	112
	S	0	42.86	57.14	N/A	N/A	0	7
	O	6.25	68.75	18.75	N/A	N/A	6.25	16
Additional support services attended	HCP	8.18	68.18	12.73	1.82	9.09	N/A	110
	S	0	57.14	28.57	N/A	N/A	14.29	7
	O	6.25	68.75	12.5	N/A	N/A	12.5	16
About me information	HCP	1.79	75.89	10.71	1.79	9.82	N/A	112
	S	0	42.86	42.86	N/A	N/A	14.29	7
	O	6.25	37.5	43.75	N/A	N/A	12.5	16

Key: HCP = Healthcare Professional, S = systems supplier, O = Other

Notes: **Blood sugar:** Is information about a person's sugar levels from their devices e.g., glucometer (fingerstick testing) or continuous glucose monitor (CGM e.g., Freestyle Libre or Dexcom G6). These include the metrics agreed by international consensus such as time in range. **Insulin:** Is information about the amount of insulin self-administered by a person at home – either by multiple daily injections or an insulin pump system etc. **Medications:** Those that they use to manage their diabetes (e.g. Metformin). **Physical activity:** The types and amounts of activities the person does e.g., steps or swimming. **Sleep:** Includes the amount and quality of the person's sleep. **Diet:** Such as the person's carbohydrate intake and food diaries. **Mental health:** Information about their mental health needs including therapies. **Self-assessments at home:** Such as PROMS or questionnaires about self- management or wellbeing e.g. Diabetes distress score. **Smoking status:** Including whether the person is a smoker or ex-smoker and how much? **Alcohol intake:** For example, how many units or drinks does the person consume weekly? **Family planning / pregnancy:** For example, is the person trying for a baby? **Measurements at home:** e.g. The person's blood pressure, blood or urine ketone tests, or body mass index. **Foot checks:** Changes to their foot health that they have noticed at home and management e.g skin changes or loss of feeling. The person's **goal setting** and self-reported progress against these. **Additional support services** that they attend related to their diabetes. **About me information:** The information about the person that they want to share with healthcare professionals including their needs, preferences, concerns and wishes e.g. what and who are important to them, how do they want to be cared for and supported. Do they care for themselves or are they supported by a carer?

N/A = Option was not available for selection.

Values highlighted in **bold** in the table are the most selected frequency.

Table 19 – Examples cited of people/ workers who may need access to PWD's diabetes information

Role(s) cited by respondent(s)
Primary healthcare workers:

GP
Practice nurses
Clinical pharmacist in primary care
Other primary care staff
Secondary healthcare workers:
Consultants (including diabetologists, vascular consultants, paediatricians, ophthalmologist)
Diabetic specialist nurses (DSNs)
Diabetes midwives
Tissue viability nurses
Acute hospital teams
Community health or care workers:
District nurses
Orthotist
Youth workers
Health visitors
Social workers
Care staff/ nursing home staff (e.g., performing delegated tasks such as insulin administration),
Social prescriber
Mental health/ IAPT services/ CMHT/ AMHT
Structured education providers (including NDPP)
Other roles/ mixed:
Dietician
Carer
Podiatrist/ multidisciplinary diabetes foot team
School support staff
Psychologist

4.12 On information recorded that HCPs need for diabetes care planning

Healthcare professionals, systems suppliers and others were asked variations of the following question:

'Which of the following information do health professionals need access to, to help a person with diabetes develop their care plan? Any comments?'

Responses were selected against a pick list of 16 information categories (see table 20).

Key points

- There was strong support from respondents that the information presented was needed to support care planning.

- For all responder groups (HCPs, suppliers, other) at least 70% of answers were selected.

Key quote(s)

Key themes from the comments were that all the information is needed for holistic care but not necessarily all the time or for all people with diabetes - to review it all in care planning would require more time for appointments. Additional information required related to a child would be information about their education.

- “You don't necessarily need all of the information, all of the time. Moreover, if we were to have everything and be expected to review it, consultation time would inevitably increase substantially” – **Endocrinologist**
- “All of these are important and are added to our clinical noting so the whole diabetes team can see the most up to date info about each of the above.” – **Dietician**
- “To make a holistic plan all of the above are needed (hence why appointments should be longer!)” **Dietician**
- “Depending on the type of contact may want additional information re: physical assessment as well as school/education for child/young person” **Hospital doctor (endocrinologist/ diabetologist/ specialist Diabetes Team)**

Table 20 – Information HCPs need to see for care planning

Which of the following information would a HCP need access to, to help a person with diabetes develop their care plan?						
Information	HCP		Supplier		Other	
	%	n	%	n	%	n
Demographics and contacts: Including the person's name and address, their professional contacts (e.g. paediatrician) and personal contacts (e.g. parent(s))	95.54%	107	100%	7	100%	17
Legal information: e.g. mental capacity assessment or made plans or advance statements for end of life care.	82.14%	92	85.71%	6	94.12%	16
Social context: e.g. smoker or ex-smoker, alcohol intake, social circumstances, occupation and working pattern, driving status	91.96%	103	100%	7	88.24%	15
Pregnancy	75.00%	84	100%	7	94.12%	16
Safeguarding and risks	92.86%	104	85.71%	6	94.12%	16
Medications and allergies	94.64%	106	71.43%	5	100%	17
Referrals e.g. for structured education and future appointments with healthcare professionals.	91.96%	103	100%	7	88.24%	15
Admission details e.g. for emergencies related to their diabetes such as hypoglycaemia or	98.21%	110	85.71%	6	100%	17

diabetic ketoacidosis or other non-diabetic conditions.						
Discharge details	90.18%	101	85.71%	6	88.24%	15
Investigation results e.g. haemoglobin A1c levels, urine ACR, lipid profile, etc.	92.86%	104	100%	7	88.24%	15
Examination findings e.g. foot check or diabetic eye screening results or other physical findings such as body mass index (weight and height).	95.54%	107	100%	7	82.35%	14
Observations e.g. blood pressure, heart rate, glucose levels from diabetes devices such as glucometers (fingerstick testing) or continuous glucose monitors (CGM).	95.54%	107	100%	7	88.24%	15
Assessments e.g. PROMS or questionnaires e.g. PAID, DDS, PHQ-9 or DRSS etc.	86.61%	97	85.71%	6	76.47%	13
Problem list	93.75%	105	85.71%	6	94.12%	16
Procedures	91.07%	102	100%	7	94.12%	16
Plan and requested actions	93.75%	105	85.71%	6	100%	17

Notes: **PAID** = Problem areas in diabetes, **DDS** = Diabetes distress scale, **PHQ-9** = Patient health questionnaire 9 item, **DRSS** = Diabetic retinopathy severity scale

4.13 On information that HCPs record in care plans currently in systems

Systems suppliers and others were asked variations of the following question:

‘Which of the following information do professionals want to agree and record in a care plan for a person with diabetes? Any comments?’

Responses were selected against a pick list of 11 information categories (see table 21).

Key points

- The total number of responses was limited but showed support respondents for the high-level information content of the personalised care and support plan standard for diabetes care planning.

Key quote(s)

Care plans must be holistic and developed with the person with diabetes and should be shared across agencies

- “Effective planning is inclusive and requires data gathering and assessment before designing a care plan with the patient which should be updated regularly and improve patient outcomes” – **Trainer in medical devices**

Table 21 – Non-professional perspective on information HCPs record in care plans

Which of the following information do professionals want to agree and record in a care plan for a person with diabetes?				
Information	Supplier		Other	
	%	n	%	n

Identifying information	100.00	7	100.00	17
GP details	100.00	7	100.00	17
About me information	100.00	7	94.12	16
Strengths	85.71	6	76.47	13
Needs, concerns or problems	85.71	6	82.35	14
Goals and hopes	85.71	6	76.47	13
Actions they want to carry out to achieve the goals	100.00	7	76.47	13
Any obstacles or barriers to achieving the goals	85.71	6	76.47	13
Confidence in achieving goals	71.43	5	64.71	11
Planned review date and responsibilities	100.00	7	88.24	15
Additional supporting and contingency plans	100.00	7	88.24	15

4.14 On planned or current pregnancy in people with diabetes

Healthcare professionals, systems suppliers and others were asked variations of the following question:

‘What information about someone’s planned or current pregnancy should be included in a record for a person with diabetes?’

Thematic analysis of responses is summarised in table 22.

Key points

- The most highly cited themes were contraception use and type (n=53), pregnancy plans and timescale (n=59), pregnancy status/ test results (n=54), PWD breastfeeding now or planning to (n=41), and PWD is actively trying to conceive (n=39).
- Themes highly cited by HCPs were history of previous pregnancies (n=13), education/advice on preconception planning/ diabetes in pregnancy offered/ given to PWD (n=12), PWD was taking folic acid at time of conception (n=7), medications review (including teratogens) (n=6), fertility status/ PWD treated under specialist fertility services (n=6), and estimated last menstrual period (LMP)/ number of weeks pregnant/ due date (n=5)

Key quote(s)

- “For general clinics we only need to know: (1) Are they pregnant, (2) are they planning pregnancy, (3) are they capable of pregnancy. Joint antenatal clinics require far more information, of course.” – **Endocrinologist**

Table 22 – Thematic analysis: Information about planned or current pregnancy in PWD

What information about a person’s planned or current pregnancy should be included in a diabetes record?			
Theme	HCP (n)	Sys. (n)	Other (n)
Most highly cited responses:			

Contraception use and type	47	0	6
Pregnancy plans and timescale	48	1	10
Pregnancy status/ test results	44	1	9
Breastfeeding (plans to or currently)	35	0	6
Actively trying to conceive (TTC)	31	0	8
History of previous pregnancies	10	0	3
Education/advice on preconception planning/ diabetes in pregnancy offered/ given	9	1	2
PWD was taking folic acid at time of conception	7	0	0
Medications review (including teratogens)	6	0	0
Fertility status/ treated under specialist fertility services e.g., In-vitro fertilisation (IVF)	6	0	0
Estimated last menstrual period (LMP)/ number of weeks pregnant/ due date	5	0	0
Other themes:			
PWD is recently postpartum	3	0	0
Mental health details of PWD	0	2	1
Family complete flag	1	0	0
Planned or unplanned pregnancy flag	1	0	0
Treatment changes during pregnancy	1	0	0
Antenatal monitoring modality	1	0	0
Professional contacts in maternity services	1	0	0
Venous thromboembolism (VTE) risk	0	0	1
Relevant blood tests	1	0	0
Dietary intake (including carbohydrate and vitamins)	1	0	0

Responses for analysis were qualitative. As such, figures above show the number of times a given theme was mentioned but are not generalisable or necessarily indicative of an overall preference or lack of the same. Some responses generated multiple themes

4.15 On additional considerations for children with diabetes

Healthcare professionals and others were asked variations of the following question:

‘What information that only applies to children is needed in a record to support a child with diabetes?’

Thematic analysis of responses is summarised in table 23.

Key points

- The most highly cited themes were observations to support growth charts and associated metrics (n=33), details of the child’s school (n=10), and details of their family situation/ support (n=9).

Key quote(s)

- “From an NDA point of view, all information would be extremely useful to review standards of care and outcomes (subject to legal considerations and the burden of collection for providers).” – **NDA representative**

Table 23 – Thematic analysis: Additional considerations for children with diabetes

Additional considerations for children with diabetes		
Theme	HCP (n)	Other (n)
Findings and observations:		
Growth charts & assoc. metrics	26	7
Height velocity	1	0
Puberty status	2	0
Developmental milestones	2	1
Birth history	0	1
School and education:		
School details	8	2
School diabetes care plan	2	3
Special educational needs	4	0
Reading age / literacy	3	0
Independence and self-management:		
Self-mx ability/ independence	1	0
Readiness for/ expected transition	2	1
Parental contact details	1	0
Family situation/ support	6	3
Child’s wishes and preferences	0	1

Responses for analysis were qualitative. As such, figures above show the number of times a given theme was mentioned but are not generalisable or necessarily indicative of an overall preference or lack of the same. Some responses generated multiple themes

4.16 On relevant tests for diabetes care used by HCPs

Healthcare professionals were asked the following questions:

‘How often do you order/ check the tests from the list below when caring for a person with diabetes? *Are there any investigations that you commonly use not listed above?*’

‘How often do you order/ check the tests from the list below when caring for a person with diabetes?’

‘What genetic tests are important in diabetes diagnosis?’ (See section 4.17)

The results related to general laboratory tests are summarised in tables 24 and 25.

Key points

- In the implementation guidance the coding (SNOMED CT) for tests for diagnosis of diabetes and those commonly used in the management of diabetes will be identified.
- The codes are included in the Unified Test List maintained by NHS Digital.
- The tests will not be constrained in the standard – setting out the commonly used tests will help implementers.
- This question was aimed at confirming the commonly used tests.

Table 24 – Some of the relevant laboratory tests in diabetes care

How often do you order/ check the tests from the list below when caring for a person with diabetes				
Investigation	Never %	Sometimes %	Nearly always %	n
Haemoglobin A1c	2.68%	11.61%	85.71%	112
Fructosamine	52.43%	45.63%	1.94%	103
Total cholesterol (TC)	16.36%	25.45%	58.18%	110
HDL cholesterol	15.89%	30.84%	53.27%	107
LDL cholesterol	16.82%	34.58%	48.60%	107
Triglycerides	17.76%	33.64%	48.60%	107
VLDL cholesterol	63.92%	24.74%	11.34%	97
Non-HDL cholesterol	34.00%	28.00%	38.00%	100
HDL: TC ratio	37.23%	34.04%	28.72%	94
LDL: TC ratio	61.96%	28.26%	9.78%	92
VLDL: TC ratio	70.21%	24.47%	5.32%	94
LDL: HDL ratio	59.38%	22.92%	17.71%	96
Albumin: creatinine ratio (ACR)	16.98%	21.70%	61.32%	106
Urinary albumin	40.21%	27.84%	31.96%	97
Urinary creatinine	42.27%	30.93%	26.80%	97
Serum creatinine	14.71%	25.49%	59.80%	102
Estimated glomerular filtration rate (eGFR) using Chronic Kidney Disease Epidemiology Collaboration Formula	12.50%	24.04%	63.46%	104
Estimated glomerular filtration rate (eGFR) using abbreviated Modification of Diet in Renal Disease Study Group Calculation	39.33%	24.72%	35.96%	89
Fasting plasma glucose	27.72%	61.39%	10.89%	101
Random plasma glucose	27.72%	53.47%	18.81%	101
Glucose tolerance test	41.58%	52.48%	5.94%	101
Insulin C-peptide level (blood)	36.54%	60.58%	2.88%	104
Insulin C-peptide/ creatinine ratio (urine)	49.49%	48.48%	2.02%	99

Glutamic acid decarboxylase (GAD) antibody	33.96%	60.38%	5.66%	106
Pancreatic islet cell 512 antibody	57.84%	39.22%	2.94%	102
Islet cell cytoplasmic autoantibody (ICA)	53.47%	39.60%	6.93%	101
Zinc transporter 8 autoantibody	60.19%	36.89%	2.91%	103
Genetic tests	52.38%	46.67%	0.95%	105

Respondents were asked to identify any investigations commonly used but not listed above (see table 25 below).

Table 25 – Other commonly used tests

Investigation	Number of times mentioned
Bedside capillary ketone	1
Bilirubin	1
Coeliac screen	15
Erythrocyte sedimentation rate (ESR)	1
Faecal elastase	2
Full blood count (FBC)	11
Doppler test*	1
Ferritin	2
Haemoglobinopathy screen	1
Haematinics	1
Radiograph (e.g. foot)	2
Haemoglobin	1
Inflammatory markers (e.g. CRP etc.)	7
IA-2A	1
Liver function tests (LFTs)	17
Monofilament test	1
Sleep study	1
TC:HDL**	1
Thyroid function tests (TFTs)	27
Vitamin D	7
Vitamin B12	2

* Specific test unspecified

** TC:HDL = Total cholesterol to high density lipoprotein ratio

4.17 On genetic tests that are important in diabetes diagnosis?

- **Summary:** Identified genetic tests are presented in table 26 below. The most common tests suggested were for MODY (n=27) or for discrimination of type 1 diabetes from MODY (n=10) and included genetic tests, autoantibody titres and the use of these with the type 1 diabetes genetic risk score.
- **Context:** Key genetic (and some other) tests identified in response to this survey question are shown in table 26.
- **Quotation:** ‘In specific patients with neonatal diabetes mellitus [the] Exeter panel [is used], i.e., for WRS/ ABCC8/ KCNJ11 etc. [If PWD has] other associated features/ conditions...[you] need BBS/ ALMS or Wolfram panel depending on features. Occasionally HNF panel for MODY and other rare forms...’ – **Diabetes specialist**
- **Action required:** Identify coding for the key genetic (and other tests) used in the diagnosis of diabetes.

Table 26 – Key genetic tests identified in the survey

What genetic tests are important in diabetes diagnosis?	
Theme	HCP (n)
Maturity Onset Diabetes of the Young (MODY) associated genes: *	27
Hepatic Nuclear Factor 1 Alpha (HNF1A)	2
Hepatic Nuclear Factor 4 Alpha (HNF4A)	2
Glucokinases (GCK)	2
Hepatic Nuclear Factor 1 Beta (HNF1B)	1
Exeter genetic lab panel	4
Neonatal diabetes mellitus (NDM): *	3
NDM caused by KCNJ11 mutations	2
NDM caused by ABCC8 mutations	1
NDM caused by EIF2AK3 mutations causing WRS **	
6q24 Transient NDM caused by PLAGL1/ HYMAI	0
Discriminating MODY from T1DM:	10
Glutamic Acid Decarboxylase 65 (GAD65) antibodies	6
Zinc Transporter 8 (ZnT8)	2
Insulinoma Antigen 2 (IA-2)	2
Type 1 diabetes genetic risk score	2
Discriminating T1DM from T2DM:	3
C-peptide	3
Tests for other conditions:	
Maternally Inherited Diabetes and Deafness	1
Islet cell cytoplasmic autoantibodies	2

Haemochromatosis	1
Cystic fibrosis	1
Insulin resistance syndromes	1
Lipodystrophies	1
Glycogen storage disease	1
Wolfram syndrome	1
Alström syndrome (ALMS)	1
Bardet-Biedl syndrome (BBS)	1
Other rare forms	1

* The latest sign off for genes approved for use in the NHS in England by Genomics England to diagnose MODY can be found [here](#) and neonatal onset diabetes [here](#).

** Causing Wolcott-Rallison syndrome (WRS)

4.18 On relevant assessments for diabetes care used by HCPs

Healthcare professionals were asked the following questions:

‘Please tell us how often you use the assessments from the list below when caring for a person with diabetes.’

‘Which assessments, if any, do you use to collect comorbidity screening data for people with diabetes?’ (See section 4.19)

‘Which assessments, if any, do you use to collect information about social isolation or digital poverty for people with diabetes?’ (See section 4.20)

The results related to general assessments are summarised in table 27.

Key points

- In the implementation guidance the coding (SNOMED CT) for assessments commonly used in the management of diabetes will be identified.
- The assessments will not be constrained in the standard – setting out the commonly used assessments will help implementers.
- This question was aimed at confirming the commonly used assessments.
- The top five most frequently reported assessments used by HCPs were Hypoglycaemia awareness or fear (Gold score, Qrisk, MUST, SINBAD)
- Other assessments identified as used in the management of diabetes were Wound assessments, Epworth Sleepyness score, MDI and carbohydrate counting assessments, PEDsQOL, WHOQOL-BREF, PREMs, mScoff for eating disorders, Leeds Assessment of Neuropathic symptoms and signs (LANSS pain scale), and PEDIS score.

Key quote(s)

- “[M]any of these are research tools, validated in populations and not validated for individual use.” – **Endocrinologist**

Table 27 – Some of the relevant assessments used by HCPs in diabetes care

Please tell us how often you use the assessments from the list below when caring for a person with diabetes.

Assessment	Never %	Sometimes %	Nearly always %	n
Diabetes distress scale 2 item	71.57%	22.55%	5.88%	102
Diabetes distress scale 17 item	73.79%	20.39%	5.83%	103
Problem areas in diabetes (PAID)	66.36%	28.04%	5.61%	107
Generalised anxiety disorder scale 2 item	82.52%	15.53%	1.94%	103
Generalised anxiety disorder scale 7 item	76.70%	19.42%	3.88%	103
Center for epidemiologic studies depression scale (CESD)	95.10%	3.92%	0.98%	102
Center for epidemiologic studies depression scale revised (CESD-R)	96.08%	2.94%	0.98%	102
Hospital anxiety and depression scale (HADS)	71.57%	25.49%	2.94%	102
Patient health questionnaire 2 item (PHQ-2)	83.33%	14.71%	1.96%	102
Patient health questionnaire 4 item (PHQ-4)	87.13%	9.90%	2.97%	101
Patient health questionnaire 9 item (PHQ-9)	70.87%	21.36%	7.77%	103
Patient health questionnaire 15 item (PHQ-15)	88.12%	9.90%	1.98%	101
Diabetes management self-efficacy scale (DMSES) UK	87.25%	11.76%	0.98%	102
Diabetes eating problem survey (DEPS)	92.08%	7.92%	0.00%	101
Diabetes eating problem survey-revised (DEPS-R)	93.14%	6.86%	0.00%	102
Malnutrition universal screening tool (MUST)	61.76%	33.33%	4.90%	102
Diabetes quality of life (DQOL) questionnaire	72.55%	25.49%	1.96%	102
Diabetic foot self-care questionnaire (DFSQ-UMA)	80.39%	12.75%	6.86%	102
Questionnaire for diabetes related foot disease (Q-DFD)	84.47%	10.68%	4.85%	103
Summary of diabetes self-care activities (SDSCA)	88.00%	11.00%	1.00%	100
Summary of diabetes self-care activities (SDSCA)	91.09%	7.92%	0.99%	101
Diabetes self management questionnaire (DSMQ)	88.35%	8.74%	2.91%	103
Patient activation measure (PAM)	82.52%	16.50%	0.97%	103
Diabetes treatment satisfaction questionnaire (DTSQ) status version	86.54%	13.46%	0.00%	104
Diabetes treatment satisfaction questionnaire (DTSQ) change version	91.18%	8.82%	0.00%	102
Hypoglycaemia awareness or fear	41.51%	35.85%	22.64%	106
Gold score	52.38%	31.43%	16.19%	105
Clarke score	73.27%	20.79%	5.94%	101
Pittsburgh sleep quality index	93.00%	7.00%	0.00%	100
PROMIS sleep disturbance scale	93.07%	6.93%	0.00%	101
General practice physical activity questionnaire (GPPAQ)	82.35%	10.78%	6.86%	102

SINBAD (Site, Ischaemia, Neuropathy, Bacterial infection, Area, and Depth)	62.86%	19.05%	18.10%	105
University of Texas wound classification system	79.21%	12.87%	7.92%	101
Young Townson FootSkin scale	94.06%	3.96%	1.98%	101
Diabetic retinopathy severity scale (DRSS)	79.21%	15.84%	4.95%	101
Medication adherence report scale (MARS)	88.24%	8.82%	2.94%	102
Morisky medication adherence scale (MMAS)	98.02%	1.98%	0.00%	101
QRISK cardiovascular disease	53.40%	28.16%	18.45%	103

4.19 On assessments to collect comorbidity screening data for PWD

- **Summary:** 26 of 112 professional responses. Most responses referred to history taking and using information in existing records rather than specific assessments.
- **Context:** This was a qualitative supplementary question.
- **Quotation:** ‘We collect information around all complications of diabetes but [I am] not aware of specific assessment tools.’ - **Endocrinologist**
- **Action required:** None.

4.20 On assessments to collect information about social isolation or digital poverty

- **Summary:** 41 of 112 professional responses were given. 20 of 41 responses indicated that they do not use a formal assessment. 15 respondents indicated that the PWD would be asked about this during a consultation or as part of a medical history. Two respondents said that the absence of certain information in the record (e.g., absence of mobile phone use) may indicate social isolation/ digital poverty. One respondent cited use of a Social Deprivation Score.
- **Quotation:** ‘We collect information around all complications of diabetes but [I am] not aware of specific assessment tools.’ - **Endocrinologist**
- **Action required:** Clarify use of Social Deprivation score and identify required codes as appropriate.

4.21 On information needed to identify PWD at risk of deterioration or harm?

Healthcare professionals and others were asked variations of the following question:

‘What information healthcare professionals need to identify people with diabetes at risk of deterioration or harm?’

Thematic analysis of responses is summarised in table 28.

Key points

- Some of the most highly cited themes were hospital admissions for diabetic complications (e.g., hypoglycaemia, diabetic ketoacidosis (DKA), or other) (n=51), unscheduled care/ emergency attendances (n=8), and comorbidities, frailties or concerns over PWD’s capacity to make a decision (n=10).

Key quote(s)

- “[Number] of admissions is always helpful. general info re engagement and key people who can be helpful e.g., homeless worker/ interpreter/ trusted family member or carer always helpful.” – **Healthcare professional**

- “My trust is relatively close to a number of other hospitals and knowing if patients have had admissions elsewhere for DKA/HHS/Hypos/ulcers is very useful.” – Endocrinologist

Table 28 – Thematic analysis: Information needed to identify PWD at risk of deterioration or harm

What information is needed to identify PWD at risk of deterioration or harm?		
Theme	HCP (n)	Other (n)
Contacts with professionals:		
Hospital admissions for diabetic complications (e.g., hypoglycaemia, diabetic ketoacidosis (DKA), or other)	41	10
Emergency attendances (e.g., Emergency department, ambulance callouts or other)	6	2
Did not attend (DNA) frequency	2	2
Other risk factors for deterioration or harm:		
Episodes of self-harm and mental health concerns	2	3
Safeguarding concerns	1	0
Comorbidities, frailty or capacity concerns	8	2
Latest test results (e.g., Hba1c, pregnancy, etc.)	8	1
Trends over time (e.g., HbA1c, glucose metrics etc)	2	3
Prescribed medications, device use & adherence	5	1
Social circumstances and support at home/ school	3	1
PWD has carer responsibility	1	0

Responses for analysis were qualitative. As such, figures above show the number of times a given theme was mentioned but are not generalisable or necessarily indicative of an overall preference or lack of the same. Some responses generated multiple themes

4.22 On information needed by HCPs about ‘Sick days’

Healthcare professionals and others were asked the following question:

‘What information do healthcare professionals need to know about sick days?’

Thematic analysis of responses is summarised in table 29.

Key points

- The most highly cited themes were monitoring including frequency (n=9) of blood or urinary ketones (n=35), capillary blood glucose (n=8), symptoms (n=22), current medications and those stopped or restarted (n=26) including insulin dosing and adjustment (n=6).
- Other themes highly cited by HCPs were whether sick day education had been provided (n=11), PWD knowledge and understanding of sick day rules (n=13) and details of their diabetes devices (e.g., glucose/ ketone monitors) (n=9).

Table 29 – Thematic analysis: Information needed by HCPs about ‘Sick days’

What information is needed by HCPs about sick days?		
Theme	HCP (n)	Other (n)
Sick day monitoring:		
Blood or urinary ketones	32	3
Capillary blood glucose	6	2
Symptoms	19	3
Fluid intake	2	0
Monitoring insulin dosing and adjustment	6	0
Monitoring frequency of the above	7	2
Current medications and those stopped or restarted	26	1
Number or frequency of sick days	3	0
PWD sick day education, knowledge, understanding, plans and situation:		
Sick day education provided	11	2
PWD knowledge and understanding	13	0
Care plan for sick days	5	1
Access to devices (and details of these)	9	0
Spare insulin pens	3	0
Ketones strips prescribed	3	1
Actions taken and the outcome of these	3	0
PWD contact details	2	0

Responses for analysis were qualitative. As such, figures above show the number of times a given theme was mentioned but are not generalisable or necessarily indicative of an overall preference or lack of the same. Some responses generated multiple themes

4.23 On requirements of systems shared by systems suppliers

Systems suppliers were asked the following question:

‘If you are a technology supplier, what are the future requirements your customers are telling you about that we should be aware of for the development of the standards?’

Thematic analysis of responses is summarised in table 30.

Key points

- See table 30 for a list of key themes.

Key quote(s)

- “Systems need to speak to each other and be interoperable. HCP's do not want to have 5 web pages up, one for each different industry partner. all diabetes tech and their digital data systems that collect the data should all feed into one system, such as [SystemOne]” – **System supplier**

- “From a national data collection point of view, it is very important that data can be extracted from systems and submitted to the audit in the least burdensome way. Data Quality is also a very important aspect of the data collection therefore robust, consistent standards across care providers are welcomed.” – **System supplier**

Table 30 – Thematic analysis: Key issues highlighted by systems suppliers

What are the future requirements your customers are telling you about that we need to be aware of?	
Theme	Suppliers (n)
Responses emphasised the need for the following:	
Interoperability/ silo reduction	3
Dashboards and iterative data	1
Alignment with national and international standards and HCP consensus statements	2
Integration of machine learning	1
Personalised health budgets	1
Support for multiple long-term conditions in systems	1
Signposted to certain peer-reviewed papers	3
Patient access to shared educational materials and platforms	2

Responses for analysis were qualitative. As such, figures above show the number of times a given theme was mentioned but are not generalisable or necessarily indicative of an overall preference or lack of the same. Some responses generated multiple themes

4.24 Other issues raised by respondents

People with diabetes, their carers or parents, healthcare professionals, systems suppliers and others were asked the following question:

‘Are there any other issues that you would like to raise?’

Key quote(s)

- “There is a real lack of education and understanding with regards to gestational diabetes. Type 2 is widely understood. But the diet and needs of [gestational diabetes] patients are completely ignored. I feel this leads to many more babies being put at risk and the parent being put on medication that could have otherwise been avoided.” – **Person with gestational diabetes**
- “The volume of information is large and I doubt that health team has capacity to look at it all. I should be able to help them with that more and also the accuracy of my information. There seems to be a lot of duplication and a lack of top line information about my health that should be at the fingertips of my health care team - i.e., my conditions, allergies, last key health checks/appointments/issues and medications. I

shouldn't be telling my diabetes consultant that I'm on thyroxine and how much. That should be there readily available to view." – **PWDT1**

- “University students with diabetes frequently change practice as they move between home and term addresses. This standard should improve their care and continuity of access to essential medication.” – **Parent of child with T1DM**
- “The use of questionnaires without reason or measure which can have a negative impact on PWD after completion and who are left to cope afterwards without support. Questionnaires are used without real need often just to measure quality of life that the questionnaire itself can impact on.” – **HCP**
- “Honestly, I do think it's brilliant to build these ideal standards. I'm hoping there is a longer term project to adapt and implement changes over time after it goes live. Things are changing overtime and we're struggling to do the bare minimum in healthcare at times. These interventions will only provide sustainable outcomes if they are able to adapt to the needs of the service. I do hope this can occur.” – **PWDT1 & HCP**

5 Easy read survey

41 people with diabetes participated in the easy read survey.

5.1 Question 1: At home what do you or your carer measure to help manage your diabetes?

Multiple options could be selected

Number of respondents	Weight	Sugar	Blood pressure	Something else
41	13 (31.7%)	31 (75.6%)	14 (34.2%)	6 (14.6%)

5.2 Question 2: Tell us anything else that you measure to manage your diabetes at home.

Free text response

- Carbohydrates - 9 respondents
- Fluid intake – 1 respondent
- Food / diet – 4 respondents
- Exercise / activity – 2 respondents
- Ketones – 3 respondents
- Blood sugars (Time in Range / glucose variability) – 4 respondents
- Sleep duration – 1 respondent
- Insulin (total daily dose) – 2 respondents

5.3 Question 3: What do you record and send to your Nurse or Doctor before you see them?

Free text response

- Blood sugar – 14 respondents
- Blood pressure – 3 respondents

- Insulin – 4 respondents

Others

- Concerns in relation to health and wellbeing including weight and footcare issues
- HbA1c (from test results)
- height, weight
- Cholesterol and renal test results (from test results)
- Calorie intake

Comments

“Consultant and DSN see CGM data but nurse at GP practice does not have access”

“What a good idea. I have not been asked to do this. I have not seen a Doctor or my specialist for 2 years because of COVID”

5.4 Question 4: What would you like to share with your Doctor or Nurse about your Diabetes?

Multiple options could be selected

Number of respondents	Any worries or fears that I have?	What treatment I like and what treatment I don't like?	How it makes me feel?	Nothing else
36	20 (55.6%)	17 (47.2%)	18 (50.0%)	4 (11.1%)

5.5 Question 5: When you see the Doctor or Nurse, do they tell you what you need to know to help manage your diabetes at home?

Single option selected

Number of respondents	They don't tell me anything about what I need to know	They tell me some things that I need to know, but not everything	Yes, they tell me everything I need to know
34	6 (17.7%)	17 (50.0%)	11 (32.35%)

5.6 Question 6: How would you like to be given more information on managing your diabetes?

Multiple options could be selected

Number of respondents	By text to my mobile phone	By a phone call to my mobile phone	By a letter sent to my home	By a face to face information session	By email sent to me
33	6 (18.2%)	5 (15.2%)	8 (24.3%)	19 (57.6%)	14 (42.4%)

5.7 Question 7: How easy did you find using this survey?

Single option selected

Number of respondents	Easy	Ok	Difficult
29	23 (79.3%)	6 (20.7%)	0 (0.0%)

6 Conclusion and Recommendations

The outputs from the survey were used to refine the standards and inform some of the project recommendations. These are discussed further in the main body of the project final report.