REC REF: 08/H0502/74

EVIDEM EoL Resident's Data Extraction Form-

1. Please give the resident ID number

2. Please give the Care Home ID number

A. TIMEPOINT (There will be a different form for each extraction point)

3. **Baseline Data**

d d m m y y y y

3. **Data Extraction 1**

d d m m y y y y

3. **Data Extraction 2**

d d m m y y yy

B. HEALTH STATUS

13. Long Term Conditions (***Please circle all that are documented)***

1 Diabetes

2 COPD
3 High blood pressure
4 Stroke
5 Heart disease
6 Dementia
7 Parkinson's disease
8 Cancer
9 Arthritis
10 Epilepsy
11 Other (Please specify)__________________________________

C. ADMISSION INFORMATION

10 a. Is there a documented diagnosis of dementia? Yes/No

If yes, please give details:

b. Type____

c. Source of diagnosis_______________________________

d. Date of diagnosis________________________________

D. Current Health Problems

14. Acute Conditions in last 2 weeks (***Please circle all that are documented)***

1. Upper respiratory tract infection

2. Chest infection

3. Flu-like illness

4. Urinary tract infection

5. Gastro-enteritis

6. Other (Please specify) _________________________________

15a. Any Falls in the last 2 weeks? Yes/No

If yes:

b. Number of falls_____________

E. ASSESSMENTS

16. Please give details of recorded assessments

Type of Assessment	Scales or Measures Used	Date Conducted	Score/Other Details
i. **Pain Assessment** Y/N	(Free text: To code when entered into SPSS)		Score ______ Not Assessed ☐
ii**. Cognitive assessment**	(Free text: To code when entered into SPSS) Eg MMSE		Score ______ Not Assessed ☐
iii. **Depression**	(Free text: To code when entered into SPSS) Eg GDS		Score ______ Not Assessed ☐
iv**. Dependency**	(Free text: To code when entered into SPSS) Eg Barthel		Score ______ Not Assessed ☐
v. **Activities of Daily Living (ADL)**	**Breathing**		1 No problems 2 Some problems 3 Immobile due to breathing problems 4 Needs Oxygen 5 Not recorded

Maintaining a safe environment		1 No problems 2 Walks with aid 3 Needs supervision to mobilise 4 Safety rail in use 5 History of falls 6 Other ________________________ 7 Not recorded
Expressing Sexuality		1 No problems 2 Needs assistance with privacy and dignity 3 Other ________________________ 4 Not recorded
Eating and Drinking		1 Self caring 2 Needs assistance of one person 3 Needs assistance of two people 4 Other ________________________ 5 Not recorded
Elimination		1 Self caring 2 Needs regular reminding 3 Needs assistance of one person 4 Needs assistance of two people 5 Incontinent 6 Not recorded
Personal Care		1 Self caring 2 Needs assistance of one person 3 Needs assistance of two people 4 Variable assistance 5 Not recorded
Sleeping		1 No problems

			2 Takes night sedation 3 Has disturbed sleep 4 Sleeps during day 5 Walks in their sleep 6 Not recorded
	Death and dying (wishes, hopes, fears)		1 Has been discussed with person 2.Not discussed 3. Not resorded Consultee involvement? Y/N
vi. **Pressure ulcer assessment**	(Free text: To code when entered into SPSS) Eg Waterlow		
vii. **Falls Risk Assessment**	(Free text: To code when entered into SPSS) Eg Fall Risk and Fracture Assessment Tool		
viii. **Manual Handling Risk Score**	(Free text: To code when entered into SPSS)		
ix**. Nutrition Assessment** Weight__ (Kg) Date_______			Not assessed ☐
x**. Other**			

Assessments			
xi**. Other Assessments**			
xii**. Other Assessments**			
xiii**. Other Assessments**			

F. Preparation for End-of-Life-Care

15. Evidence of Physical Decline towards the End-of-Life

(Please tick one box) Yes ☐ No ☐

If ***Yes*** *please circle all codes that apply:*

1 Falling

2 Infections

a chest infection/pneumonia

b urinary tract infection

c septicaemia

d skin infections

e other please state____________________

3 Chair bound

4 Bed bound

5 Incontinence: a urine; b faeces

6 Diarrhoea

7 Vomiting

8 Pressure areas: skin breakdown

9 Increased confusion

10 Eating and Drinking

a loss of appetite

b weight loss

c difficulty in swallowing

d supplementary feeds

e unable to eat

f unable to drink

11 Contractures

12 Other (please specify) _________________

13 Not recorded

16. Is there evidence of the resident being actively involved in advanced planning or in the assessment, care planning and evaluation process for end-of-life care?

(Please tick all that apply)

Resident Yes No ☐ ☐

Consultee involvement? Yes No ☐ ☐

Family involvement Yes No ☐ ☐

Please give details____

17. Preferred place for end-of-life care

(Please circle code that applies)

1 Care home
2 Hospice
3 Hospital
4 Other (please specify)______________________________
5 Not recorded

18. Use of Protocols for End-of–Life Care

(Please circle codes that apply)

1. Care home specific
2. Organisation specific (please specify)__________________

3. Gold Standard Framework (Care Home) GSFCH
4. Liverpool Care Pathway LCP
5. Preferred Place of Care PPC
6. Other (please specify)____________________________
7. Not documented

G. TOTAL SCORE OF ALL ASSESSMENTS

ASSESSMENT	TOTAL SCORE	DATE and COMMENTS
Disability Assessment for Dementia (DAD)		
Cornell Scale for Depression in Dementia (CSDD)		
Cohen-Mansfield Agitation Inventory (CMAI)		

CLIENT SERVICE RECEIPT INVENTORY

A

1. Please state the name of the organisation that manages the facility and *tick* whether this is local authority social services, an NHS organisation, private (for-profit) organisation, voluntary (non-profit) organisation or other.

____

☐ *(social services)* ☐ *(NHS)*

☐ *(private)* ☐ (voluntary) ☐ (other)

2. What is the **total** weekly charge per week for the resident?

£ ☐☐☐☐

3. Who contributes towards the cost of this placement? ***(Circle all codes that apply)***

1 DSS	5 Resident
2 National health service	6 Resident's family
3 Local authority	7 Insurance policy
4 Voluntary organisation	8 Other *(please specify)*______________________

If no, go to question 6

4. Has the service user lived <u>anywhere else</u> during the last three months?

(excluding hospital stays)

Yes No

☐ ☐ →

5. If yes to Question 4, what type of accommodation was this?

Accommodation type	**Approximate number of nights spent in this accommodation in last 3 months**
Nursing home	
Other *(please specify)*____	

B. SERVICE RECEIPT

6. Please list any use of the following **hospital services** over the last 3 months

Service	**Name of ward, clinic, hospital, centre**	**Reason for using service**	**Number of contacts**
Accident & Emergency			__________ visits
Hospital inpatient ward in an acute hospital			________inpatient days
Community Hospital ward			_______inpatient days
Day hospital			_______attendances
Outpatient services (list all)			_______appointments
			_______appointments

			________appointments
			________appointments
Other (Please specify):			

7. Please list any use the service user has made of **community-based services** over the last 3 months. ***Code outpatient services at Q8 above***

Primary Care, Community Health and Emergency Services*	***Tick if yes***	**Total number of contacts**	**Typical duration of contact (mins)**
Paramedic (ambulance service)			
Community Matron			
Community/District Nurse			
Practice Nurse			
Night Nurse			
Specialist nurse *e.g.*palliative *care, continence, diabetes*		________home ________office	________home ________office
Occupational Therapist			
Speech and language therapist		________home	________home

		________office	________office
Physiotherapist		________home ________office	________home ________office
General practitioner		________home ________office ________phone	________home ________office ________phone
Other community doctor, *describe:*		________home ________office ________phone	________home ________office ________phone
Palliative care services e.g. Marie Curie nurse, hospice outreach			

Social Care	***Tick if yes***	**Total number of contacts**	**Typical duration of contact (mins)**
Social worker or Care manager		________home ________office ________phone	________home ________office ________phone
Sitting scheme (e.g. Crossroads, Marie Curie)			
Voluntary sector e,g, Age Concern befriending service, 'pet a dog'			

Community Mental Health Services	*Tick if yes*	Total number of contacts	Typical duration of contact (mins)
Psychiatrist		____home ____office	____home ____office
Psychogeriatrician		____home ____office	____home ____office
Psychologist		____home ____office	____home ____office
Counsellor		____home ____office	____home ____office
Community psychiatric nurse/ Community mental health nurse		____home ____office	____home ____office
Other mental health professional, describe:		____home ____office	____home ____office
Other mental health professional, describe:		____home ____office	____home ____office

Adaptations, Equipment and products	*Tick if yes*	**Type of adaptation or equipment *(list all)***	**Who supplied this?**	**Who/what organisation paid for this?**
Special equipment *(e.g. for mobility, pressure area care, safe moving and handling, pain management (syringe driver).*			*Equipment provided by NHS and those by CH included in fees?*	
Continence products (*e,g., pads, pull up pants*)			Supplied NHS or in CH fees?	
Aids to getting to and using the toilet or protecting bedding/furniture(*e.g. raised toilet, urinal bottles*)				

Other services: e.g. dentist, optician, chiropodist, other social care	***Tick if yes***	**Total number of contacts**	**Typical duration of contact (mins)**	**Who/what organisation paid for this? (eg NHS, purchased by individual, included in CH fees)**
1.				
2.				
3.				

8. Please list any use of the following **day services** over the last 3 months

Day Services	***Tick if yes***	**Name of centre/ service**	**Number of contacts per week**	**Total number of contacts over last 3 months**
Day care – local authority social services department			______________Days	
Day care – voluntary organisation			______________Days	
Day care – NHS (community-based)			______________DaYs	
Social activities *(Include activities inside care home, or external activities)*			_____________Visits	
Patient education/Expert Patient group - Please describe:			_____________Visits	
Exercise class *(Include activities inside care home, or external activities)*			__________Sessions	
Other				

9. Please list below use of any medications taken over the last 3 months (write additional on separate sheet)

Name of medication	**Dosage (if known) (mg)**	**Dose frequency (e.g. daily)**	**For how long has service user taken this drug?**
1.			
2.			

3.			
4.			
5.			
6.			
7.			
8.			
9.			
10.			
11.			
12.			

C. BENEFITS *(Difficult to obtain from residents in CHs, only likely receive state pension and, for the minority, a private pension. Not entitled other payments if LA funding CH placement)*

11. Over the past 3 months have you received any of the following payments? (include payments made jointly to others in household)

	Service user (tick as many as apply)	**Other member of household (describe which)**	**How long has service user received this benefit (in weeks, over the last 3 months)**
State Retirement (old age) Pension			
A Widow's or War Widow's Pension			
Pension Credit			
War disablement Pension			
Any other state benefit not listed (please state)			

Any other state benefit not listed (please state)			
Any other state benefit not listed (please state)			