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Coding Unpaid Carers: SNOMED CT

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Introduction

1. An unpaid carer is anyone including children and adults who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid. When we refer to carers in this document, this is inclusive of both adult and [young carers](#) (under 18). The law is very clear about who is an unpaid carer.
2. The [NHS Long Term Plan](#) (LTP) makes a clear commitment to identify and support unpaid carers. There are clear metrics associated with supporting young carers and ensuring professionals can access carer contingency plans when they need to (See Annex A).
3. [The LTP Top Tips for Young Carers](#) made clear that young carers want access to preventive health and social prescribing and timely referral to local support services.
4. The 2021 White Paper, [People at the Heart of Care](#), also makes clear: *We [DHSC] will look to increase the voluntary use of unpaid carer markers in NHS electronic health records by simplifying current approaches to data collection and registration. We will also introduce a new marker indicating the presence of a contingency plan, where one is available, that describes the actions to take if the carer is no longer able to provide care.*
5. Carers were included in JCVI Cohort 6 priority group for COVID-19 vaccinations and associated boosters. [Version 2 of the COVID-19 standard operating procedure](#) has multiple references to putting a “carer’s flag” on primary care records “as this provides a sustainable approach for identifying unpaid carers”. The [“Adult primary care COVID-19 assessment pathway”](#) identifies people with caring responsibilities as a higher risk.
6. [Public Health England](#) made clear that Caring should be considered as a social determinant of health.

7. The [GP Quality Markers](#) provides a framework for improving how General Practice can identify and support carers, including how the practice can use its carer's register to support holistic carer health and wellbeing needs.

Clinical Coding Review

8. There is a need to improve the identification, recognition and support of unpaid carers as part of proactive prevention approaches being pursued at a population health level.
9. Some GP practices have developed a register of their patients known to have caring responsibilities. There will be large differences in the scale and accuracy of these registers. Not all carer registers are linked to patient records.
10. Where carer registers are coded and linked to patient records, this has not been done consistently. There are >80 existing SNOMED CT codes which relate to unpaid carers, or which could be perceived to relate to unpaid carers. As such, primary care data for unpaid carers isn't consistent.
11. This guidance sets out a recommended cluster of SNOMED CT codes for unpaid carers, of all ages, to enable and demonstrate the delivery of the NHS Long Term Plan and People at the Heart of Care. Consistency when coding unpaid carers will help to ensure that carers are better identified and supported across and within systems.
12. As a minimum systems are expected to be able to report how many unpaid carers are registered in primary care, including the number of young carers, and of those unpaid carers, how many have a carer contingency plan recorded in records so that professionals can action them when required.

SNOMED CT codes for unpaid carers

13. It is recommended that as a minimum data set unpaid carers are coded as follows using one of the below SNOMED CT codes:

SNOMED CT code	Term Description	Definition for NHS LTP delivery and associated metric
224484003	Patient themselves providing care	Person who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid.
302767002	Cares for a relative	Person who looks after a family member who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid.

14. It is recommended that as appropriate unpaid carers are coded as follows using the below SNOMED CT codes:

SNOMED CT code	Term Description	Definition for NHS LTP delivery and associated metric
1366321000000106	Has Carer Contingency Plan/ Has Carer Emergency Plan	Carer has contingency plan in place for a situation when they cannot provide care and relevant information is accessible to professionals.
199361000000101	Is no longer a carer	When a person is no longer providing care unpaid.

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