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Primary care models for community-dwelling adults with long-term conditions: a scoping review protocol

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1 Introduction

2 Worldwide, health has been shaped by both the environment in which people live and the resources
3 available¹. For most, this has increased life expectancy over the last ten years with little fluctuation.
4 Adults in the United Kingdom (UK) who are currently 60 years of age are predicted to live for a further
5 20 years². In addition to these people living longer, a significant percentage are also living with one or
6 more **long term conditions**³. Long term conditions are defined as conditions that require ongoing
7 management over a period of years or decades⁴, **also** known as noncommunicable diseases, which
8 comprise conditions such as heart disease, stroke, cancer, chronic respiratory diseases and diabetes,
9 are the primary cause of mortality globally⁵. These conditions can fracture the economic development
10 of many countries and the number of individuals, groups and communities affected by the impact of
11 **long term** illness is increasing⁶. Advances in healthcare have seen conditions that were once thought
12 to be life limiting, becoming those that people live with for many years⁷. Although appearing to be an
13 achievement for humanity, this also presents a global challenge to health care systems due to the
14 increased prevalence of those living with complex and enduring conditions. People who live with
15 these conditions often require high levels of health and social care due to the complexity that living
16 with a long term condition entails⁸.

17 It is well established that living with a long term condition impacts on the quality of life, health
18 outcomes and the ability to carry out daily activities⁹. For example, research has highlighted
19 experiencing fear, blame, struggling, fatalism, and hidden disability as key themes for those affected
20 by chronic obstructive pulmonary disease¹⁰. The possibility of developing a mental health condition
21 also increases with the number of physical illnesses a person experiences¹¹. This demonstrates the
22 need for services to be equipped to support those with both physical and mental health conditions
23 effectively. Generally, services are specialist to one pathological condition and therefore the care and
24 support provided to those with multi factorial illnesses can be fragmented and disjointed, leading to
25 errors and omissions¹². Clinical evidence and guidelines are largely created for individual diseases
26 and specialized to a single illness, demonstrating the lack of guidance for those supporting people
27 with multiple long term conditions. Likewise, most randomized trials exclude multimorbidity and older
28 people within their sampling strategies, thus not generating the evidence that could support the
29 development of understanding within this areas of practice for many health professionals¹³.

30 Global impact of Long Term Conditions

31 In Australia, 35% of the population have a long term condition, and an increasing number have
32 multiple conditions, making care increasingly complex with input required from a range of health
33 professionals¹⁴. Similarly, the health and social care systems within the UK are facing unprecedented
34 pressures due to the high volumes of people who require support compounded by the effects of long
35 term governmental austerity policies¹⁵. Many people with long term conditions, are frequent users of
36 acute hospitals, primary care and social care services, thus increasing pressures on services that are
37 already overwhelmed⁸. Within the United States of America, long term conditions represent the

38 leading cause of morbidity and mortality with over 70% of all deaths being attributable to heart
 39 disease, cancer, stroke, chronic obstructive pulmonary disease, and diabetes¹⁶. In New Zealand,
 40 long term conditions account for 88% of healthy life lost due to factors including premature death,
 41 illness or impairment¹⁷. Health systems globally are in need of strategic refocus due to the challenges
 42 being brought about by how our societies have developed. However, it is imperative not to ignore
 43 those societies where the impact of long term conditions is significant, despite some differences in
 44 their aetiology, compared with the challenges posed by long term conditions to westernized society.
 45 An example might be Sub-Saharan Africa, stereotypically recognized as a region with high levels of
 46 malnutrition, yet, identified more recently, due to growth in urbanization and westernization, with a rise
 47 in obesity¹⁸. Universally, the physical impact on the earth of global warming has had and will continue
 48 to have a significant impact on human health, especially for those with long term conditions perhaps
 49 through injury during natural disasters, malnutrition during famine or inability to cope physiologically
 50 with the effects of prolonged heat waves. The impact is amplified for those living in low-income
 51 countries¹⁹. Furthermore, direct exposure to natural disasters has an impact on mental health and
 52 conflict has been reported as a major threat to public health however, the lasting effects of conflict on
 53 health have yet to be studied in the context of developing countries²⁰. In spite of developing countries
 54 representing the majority of the world's population and 90% of the worldwide burden of disease²¹
 55 research and development is substantially inadequate^{22,23}. Under-representation caused by lack of
 56 capacity and commercial viability hinders health improvement in regions where research led
 57 resolutions could have the greatest impact to life^{24,25}. The health and social care systems within
 58 developing countries require evidence to guide resolutions regarding the most efficient and cost-
 59 effective interventions for those with long term conditions.

60 Primary Care

61 The World Health Organization's analysis of health systems⁵ demonstrates gaps within health care,
 62 most noticeably within primary care, presenting barriers to the provision of equitable health care for
 63 people living with long term conditions. Primary care is the first point of contact with health systems
 64 and is also the point of access for people to receive care for most of their everyday health and well-
 65 being needs²⁶. Primary care services include health promotion, disease prevention, health
 66 maintenance, counselling, patient education, diagnosis and treatment of acute and chronic illnesses²⁷.
 67 Over the past two decades, several countries worldwide have initiated reforms to improve their
 68 delivery of primary health care with the intention of supporting those with long term conditions to
 69 manage their condition better and reduce the risk of unplanned hospital admissions^{7,28,29,17}.

70 Long-term solutions to support those with long term conditions need to be created in order to increase
 71 health service capacity, provide cost-effective solutions whilst, most importantly, ensuring people
 72 receive the best services, in order to live meaningful and productive lives. UK Policy is focusing
 73 heavily on delivering care nearer to the patient with the aim of increasing self-care and improve
 74 management of those with more complex long-term conditions, prevent hospital admissions and
 75 improve quality of life for individuals⁷. However, it is imperative that new models of care consider that

76 people with a long-term condition should be supported to live and not just exist¹⁵. Long-term
77 conditions have a wide-reaching social impact, affecting every part of an individual's daily life,
78 including family relationships, employment and everyday socialization. Models of healthcare often
79 focus on symptom reduction, disease management, and basic prevention, and not on the pursuit of
80 long-term health. Recent research has highlighted a rise in emergency readmissions for conditions
81 that are classified as “potentially preventable” between 2010 and 2017 by 41.3%. Such admissions
82 are also contrary to the preferred wishes of most patients who wish to be cared for at home²⁹.

83 Essentially, people with complex health needs are not properly supported³⁰. More than a quarter of
84 people who have long-term conditions say that they are not well cared for by their healthcare provider,
85 and 40% expect their care to get worse in the future²⁸. People report frustration by using different
86 services that do not communicate and share information, therefore people are left feeling that their
87 conditions are treated in isolation²⁸. Well-designed primary care has the potential to improve health
88 and cost effectiveness however, large gaps exist in the evidence base concerning care for patients
89 with multimorbidity³¹. A recent Cochrane review³² found only 18 trials that evaluated models of care
90 with two main strategies: the reorganization of care delivery through enhanced multidisciplinary
91 working, and patient-oriented education or self-management. The review found limited evidence for
92 the effectiveness of the models with a lack of agreement regarding the description of models of care
93 for multi morbidity. However, the process of evidence building is hindered by incomplete descriptors
94 of models within publications³³. Without accurate descriptions of these developing models,
95 researchers cannot replicate studies or identify components for success.

96 Producing a scoping review of the literature surrounding models of primary care for long term
97 conditions would allow researchers and health care professionals to further understand current and
98 emerging models of practice in order to more effectively recognize what models of practice work for
99 different individuals, communities and populations³³. This information is likely to be critical, given the
100 broad range of approaches and patient populations included under the umbrella of long term
101 conditions. Due to the heterogeneity of the research base and differing approaches to implementing
102 primary care models to support those with long term and complex conditions, a scoping review will
103 provide a rigorous and transparent method of mapping this concept as a preliminary step to further
104 research and evaluation. The objective of this review is to map the available evidence to provide an
105 overview of the existing primary care models of practice that aim to improve clinical and mental health
106 outcomes and patient-reported outcomes for people with long term conditions that are community
107 dwelling.

108 A preliminary search of PROSPERO, MEDLINE (Ovid), the Cochrane Database of Systematic
109 Reviews and the Joanna Briggs Institute Database of Systematic Reviews and Implementation
110 Reports was conducted and no current, or proposed, systematic reviews on the exact topic of this
111 planned review were identified. However, a rapid review by Singh and Ham³⁴, conducted in 2005 was
112 identified and, although the rapid review provides insight into frameworks for people with long term
113 conditions internationally, it was only able to capture readily available literature over a short period of

114 time, thus not permitting systematic appraisal of all of the research within this field. Due to the
 115 significant demographic and social changes and development of healthcare designed for those with
 116 long term conditions over the intervening 15 years, it is essential that this topic is explored
 117 comprehensively, examining the effectiveness of contemporary primary care models focussed on
 118 those living with long term conditions, which this scoping review aims to achieve.

119 Review Questions

120 What primary care models exist globally for adults with long term conditions?

121 What are the characteristics, outcome measures used to evaluate, the impact reported, and the
 122 implications for practice of the models of primary care identified?

123 Keywords

124 Chronic Disease; Community Health Services; Long term conditions; Primary Health Care

125 Inclusion Criteria

126 Participants

127 The review will consider studies that include adults that live with long term conditions. This will
 128 exclude evidence of those who have long term conditions but are under the age of 18. For the
 129 uniformity of this review, the term used throughout will be long term conditions although it has been
 130 noted that a multitude of definitions exist in the literature that encompass 'long term conditions'.
 131 Interchangeable terms for long term conditions include; chronic conditions, chronic illness and chronic
 132 disease, as well as a term identified by the World Health Organization³⁵, noncommunicable disease.
 133 The Department of Health⁴ defined a long term condition as: 'One that cannot currently be cured, but
 134 can be controlled with the use of medication and/or other therapies' (p.3). Long term conditions are
 135 also defined as conditions that require ongoing management over a period of years or decades and
 136 cover a range of health conditions that go beyond the conventional definition of chronic illness, such
 137 as heart disease, diabetes and asthma³⁶. Multimorbidity is also a prevalent term within relevant
 138 literature, referring to the presence of two or more chronic medical conditions in an individual³⁷. Long
 139 term conditions also comprise some communicable diseases, such as the human immunodeficiency
 140 virus and the acquired immunodeficiency syndrome (HIV/AIDS) that, due to advances in medicine,
 141 have become controllable health problems although they are communicable. The term, long term
 142 condition also extends to mental health conditions such as depression and schizophrenia and
 143 disabilities and impairment including blindness and musculoskeletal disorders³⁶. Whilst there remains
 144 some ambiguity regarding a sole definition, the common denominator is that they all require a
 145 complex approach to their care that is often over the course of the lifespan from the onset of the
 146 condition. In relation to the participants, this scoping review will have a global approach and therefore,
 147 will take into consideration any evidence internationally, published in English that investigates primary

148 care models for adults with long term conditions. This is to capture all the evidence available to create
 149 a scoping review that has the potential to have international value for primary care.

150

151 Concept

152 The concept being mapped within this scoping review will be primary care models used to manage
 153 individuals with long term conditions. The concepts of interest are the characteristics (values,
 154 principles, components and suggested practical applications), outcome measures, impact and
 155 implications for practice of the models of primary care identified. Within the literature, a number of
 156 different terms such as service delivery models of care and service frameworks have been used
 157 interchangeably to articulate the way in which services are or should be conducted. For the purpose
 158 of this review, all characteristics of a model of service delivery, either in part or as a whole, will be
 159 considered; this may include services, models, interventions, frameworks that involve primary care of
 160 patients. This may also encompass services not solely designed for long term conditions however,
 161 they will be services that may be the first port of call for those with long term conditions. Therefore,
 162 the focus of the search will include literature that involves specifically primary care models,
 163 interventions and similar concepts that are defined by similar boundaries of service design and
 164 implementation but lack use of the term, 'primary care intervention'. It is recognized that many service
 165 developments are not subjected to rigorous evaluation, but still may provide useful examples of the
 166 way in which primary care services have been developed. Therefore, the review will also encompass
 167 current developments in clinical practice in relation to long term primary and community care.

168 An operational a priori criteria has been developed in order to distinguish primary care models from
 169 similar community models:

170 1) The care provided is within a primary care setting e.g. General Practice (GP) surgery, community
 171 center or through adult social care

172 2) Care is longitudinally coordinated by health and social care professionals

173 3) Care may be delivered in the patient's home, through information technology or within a voluntary
 174 third sector settings

175 4) Care can include telecare and case managers; however, there must be clear and evident oversight
 176 and integration of patient care by the primary care physician or team

177 All four criteria need to be met for a paper to be included. Models that do not utilize the term "primary
 178 care", but met the four operational criteria, will be included in the review.

179 Context

180 This review will focus on the context of primary care. Therefore, this review will consider studies that
 181 examine primary care models within a global context, due to the scope of the literature available. A
 182 preliminary review of the literature demonstrates that the development of primary care models will be
 183 of worldwide interest. Searching will be restricted to English language because due translation
 184 resources are not available.

185 Types of Sources

186 This scoping review will consider both experimental and quasi-experimental study designs including
 187 randomized controlled trials, non-randomized controlled trials, before and after studies and interrupted
 188 time-series studies. In addition, analytical observational studies including prospective and
 189 retrospective cohort studies, case-control studies and analytical cross-sectional studies will be
 190 considered for inclusion. This review will also consider descriptive observational study designs
 191 including case series, individual case reports and descriptive cross-sectional studies for inclusion.
 192 Qualitative studies will also be considered that adopt methodologies including, but not limited to
 193 phenomenology, grounded theory, ethnography, qualitative description, action research and feminist
 194 research. In addition, systematic reviews that meet the inclusion criteria will also be considered.
 195 Additionally, text and opinion papers, as well as other published material such as case studies,
 196 relevant academic presentations, such as theses and dissertations, will also be included. Official
 197 websites of organizations be used as a source of unpublished information and, together with
 198 international strategies on public health, including, but not limited to white papers, reports, position
 199 papers, policy papers, governmental guidance that are available in print or online.

200 Literature published from 1995 onward will be considered for the review. 1995 is the date that Wagner
 201 published The Chronic Care Model³⁸, a framework for describing the essential elements needed to
 202 provide the best quality care for those with long term conditions. This model is frequently drawn upon
 203 in more contemporary evidence so this date becomes a clear starting timeline for the development of
 204 the search for models for long term health conditions.

205 Methods

206 Search strategy

207 The search strategy will aim to locate both published and unpublished studies. The proposed
 208 systematic review will be conducted in accordance with the Joanna Briggs Institute methodology for
 209 scoping reviews³⁹. A three-step approach to searching is proposed in line with Joanna Briggs
 210 Institute recommended methodology³⁹. An initial limited search of MEDLINE was undertaken to
 211 identify articles on the topic. An example of the search strategy has been appended (see Appendix
 212 I). The text words contained in the titles and abstracts of relevant articles, and the index terms used to
 213 describe the articles were used to develop a full search strategy. The search strategy, including all

214 identified keywords and index terms will be adapted for each included information source. It is
 215 acknowledged that an iterative approach will be used and further search terms may be revealed and
 216 utilized within the search strategy.

217 The reference list of the identified articles will be reviewed to include other relevant studies and
 218 additional items. Duplicate sources and publications that do not directly relate to the research
 219 question will be eliminated. The title and abstract of each article will be reviewed thoroughly to select
 220 the most relevant sources

221 Information sources

222 Searches will be undertaken using the following electronic databases: MEDLINE, Embase and
 223 PsycINFO via Ovid interface, HMIC, CINAHL, Cochrane library and Web of Science.

224 Other searches will be undertaken through ProQuest Dissertations and Theses Global and Google
 225 Scholar. A pragmatic decision to review only the Google Scholar articles from the first fifty pages was
 226 taken following consultation with an information specialist. EthOS (British Library Theses online
 227 service) is accessible via ProQuest Dissertations and Theses Global. The appended search strategy
 228 will be employed to capture any grey literature using Open Grey.

229 Supplementary searching will include hand searching of the data yielded and hand searching within
 230 relevant journals including but not limited to; Quality in primary care, Journal of primary care and
 231 community health, Journal of family medicine and primary care, Journal of Integrated care,
 232 International journal of integrated care, Journal of primary health care, British journal of general
 233 practice and Canadian family physician. It is envisaged that these journals will form part of this search
 234 and others will be searched according to their value to the research questions. Hand searching within
 235 relevant conference abstracts such as the primary care and public health conferences, white papers,
 236 reports, professional bodies, charities and news articles will also be utilized. Lexus library will be
 237 searched to capture any new articles of relevance. Further to this, the reviewers intend to contact
 238 authors of primary studies or reviews for further information if necessary.

239 Study selection

240 Following the search, all identified citations will be collated and uploaded into the bibliographic citation
 241 management system, Endnote VX.X (Clarivate Analytics, PA, USA) reference manager. Titles and
 242 abstracts will then be screened by two independent reviewers for assessment against the inclusion
 243 criteria for the review. Potentially relevant studies will be retrieved in full and their citation details
 244 imported into the Joanna Briggs Institute's System for the Unified Management, Assessment and
 245 Review of Information (JBI SUMARI). The full text of the selected citations will be assessed in detail
 246 against the inclusion criteria by two independent reviewers. Reasons for exclusion of full text studies
 247 that do not meet the inclusion criteria will be recorded and reported in the systematic review. Any
 248 disagreements that arise between the reviewers at each stage of the study selection process will be

249 resolved through discussion, or with a third reviewer. The results of the search will be reported in full
 250 in the final systematic review report and presented in a Preferred Reporting Items for Systematic
 251 Reviews and Meta-analyses (PRISMA) flow diagram⁴⁰.

252 Data Extraction

253 Data will be extracted from papers included in the scoping review by two independent reviewers using
 254 a data extraction tool developed by the reviewers. The data extraction process may also be referred
 255 to as charting the results when utilised within a scoping review. Charting of the data will include
 256 specific details about the population, concept, context, study methods and key findings relevant to the
 257 review objective. A data extraction instrument has been created explicitly for this scoping review (see
 258 Appendix II). The data extraction instrument will be modified and revised as necessary during the
 259 process of extracting data from each included study. Modifications will be detailed in the full scoping
 260 review report. Any disagreements that arise between the reviewers will be resolved through
 261 discussion, or with a third reviewer. Authors of papers will be contacted to request missing or
 262 additional data, where required.

263 Data Presentation

264 The extracted data will be presented in tabular form in a manner that aligns with the objective of this
 265 scoping review. A narrative summary will accompany the tabulated and/or charted results and will
 266 describe how the results relate to the reviews objective and questions.

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273 Conflicts of interest

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 275 interest.

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386 Appendices

387 Appendix I: Search strategy

388 Search Terms

389

390 1. Primary Healthcare or Primary adj2 care or Community or Healthcare or Public Health or Health
 391 promotion

392 2. Model* or Service* or Intervention* or Framework* or Innovation* or Approach* or Strateg* or
 393 Method* or Deliver* or Program* or Facilit* or Provision* or Management or Design* or Education* or
 394 Guideline* or Guidance or Project* or Protocol* or Implement* or Pathway* or Evaluat*

395 3. 1 and 2

396 4. Comorbidity OR Co-morbidity OR Multimorbid* OR Multi-morbidity OR Chronic* adj3 Disease* OR
 397 Ill* OR Condition* OR Health* OR Syndrom* OR Symptom* OR Complex OR Multimorbidit* OR Long
 398 term condition* OR diabetes mellitus OR diabet* OR hypertension OR hypertens* OR "high blood
 399 pressure?" OR heart diseases OR heart OR cardiac OR cardiovascular OR coronary adj disease? OR
 400 disorder? OR failure OR arrythmia OR cerebrovascular disorders OR cerebrovascular OR vascular
 401 OR carotoid OR arter* adj disorder? OR disease? OR asthma OR asthma* OR pulmonary disease
 402 OR chronic obstructive OR copd OR pulmonary adj2 disease? OR disorder? OR cerebrovascular OR
 403 brain ischemia OR cerebral infarction OR stroke OR hyperlipidemia OR hyperlipidem* OR
 404 Hypercholesterolemia* OR hypertriglyceridemia*or Thyroid diseases OR thyroid adj disease? OR
 405 disorder OR hyperthyroid* OR hypothyroid* OR arthritis rheumatoid OR rheumatoid arthritis OR
 406 rheumatic diseases OR rheumati* OR fibromyalgia OR back OR neck OR chronic adj pain OR
 407 musculoskeletal OR Dementia OR Alzheimer adj Disease OR dementia OR mental disorders OR
 408 mental OR anxiety OR mood OR psychological OR sleep adj disease? OR disorder? OR depression
 409 OR schizophren* OR psychos* OR addiction? OR epilepsy OR epileps* OR seizure? OR hiv
 410 infections OR HIV OR acquired immune* deficiency syndrome? OR aids adj associated OR related
 411 OR arteritis OR neoplasms OR neoplasm? OR cancer? OR kidney diseases OR kidney adj disease?
 412 OR disorder? OR liver diseases OR liver adj disease? OR disorder? OR osteoporosis cystic fibrosis
 413 OR nervous system disease* OR brain adj disease* OR damage* OR injur* OR neurodegenerative
 414 OR Hunting* OR Parkinson* OR sclerosis OR multiple sclerosis OR muscular dystrophy OR motor
 415 neur* OR paralys* OR quadriplegi* OR tetraplegi* OR paraplegi* OR locked-in syndrome OR hearing
 416 loss OR hearing aid* OR deaf* OR blind* OR down* syndrome.tw. OR cerebral palsy OR nutrition
 417 disorders OR underweight OR malnutrition OR malnourished OR overweight OR obes*

418 5. 3 and 4

419

420 Appendix II: Data extraction instrument

Author	Year of publication	Country of origin	Model/ Intervention	Aim	Study design	Study population, sample size	Characteristics of Model/ Intervention	Outcomes assessed	Results/ Findings/ Recommendations	Implication for practice, further study

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