



Nodi a rhagweld yr angen am ofal diwedd oes: Adolygiad ystwyth o'r llenyddiaeth

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Mae'r adolygiad ystwyth hwn yn amlinellu canfyddiadau chwiliad a gynhaliwyd gan y Gwasanaeth Tystiolaeth i nodi ffynonellau sy'n disgrifio nodweddion (personol ac sy'n gysylltiedig â gofal iechyd) mewn cysylltiad ag anghenion y boblogaeth ar gyfer gofal diwedd oes neu ofal lliniarol. Mae'n cwmpasu nifer o gwestiynau a ddaeth i law wrth i ni archwilio'r dirwedd dystiolaeth. I ddechrau, gwnaethom nodi modelau a ddefnyddir i ragfynegi'r angen ar lefel y boblogaeth am ofal lliniarol yn y dyfodol, ac yna astudiaethau sylfaenol yn defnyddio'r modelau hyn i nodi nodweddion penodol pobl y mae angen y gofal hwn arnynt. Yn olaf, nodwyd astudiaethau sylfaenol eraill a oedd yn disgrifio nodweddion pobl a dderbyniodd neu a allai fod angen gofal lliniarol. Bydd y gwaith hwn yn helpu i lywio datblygiad asesiad o'r effaith ar anghenion o ran gofal lliniarol yng Nghymru.

Cwestiwn yr adolygiad	
<i>Pa nodweddion a ddefnyddiwyd yn flaenorol fel dangosyddion i ragweld ar lefel y boblogaeth, pwy allai fod angen gofal diwedd oes?</i>	
Sampl	Pobl sydd angen gofal diwedd oes (a ddiffinnir fel y rhai yn 12 mis olaf eu bywyd)
Ffenomen o ddiddordeb	Nodweddion ar lefel y boblogaeth o'r bobl sydd angen gofal diwedd oes
Dyluniad	Asesiadau o anghenion y boblogaeth, astudiaethau modelu, astudiaethau gwerthuso
Gwerthusiad	Nodweddion personol a gofal iechyd gofal diwedd oes ar lefel y boblogaeth a ddefnyddiwyd fel dangosyddion
Math o ymchwil	Dulliau meintiol, ansoddol a chymysg
Ystyriaethau Eraill yr Astudiaeth	
Dim cyfyngiadau o ran dyddiad cyhoeddi	



Pa dystiolaeth a nodwyd gennych oedd yn mynd i'r afael â'ch pwnc?

1. Negeseuon allweddol

- Nodwyd sawl model i ateb y cwestiwn cyffredinol *faint o bobl sydd angen gofal lliniarol ar lefel y boblogaeth?*
- Ni aseswyd modelau oedd yn rhagweld a nodi'r rhai sydd angen gofal lliniarol ar sail unigol
- Bu pob model yn edrych ar yr angen cyffredinol am ofal lliniarol ac roedd pum model yn ymgorffori'r gallu i gyfrifo angen yn seiliedig ar wahanol sefyllfaoedd rhagweld
- Roedd pum model yn cynnwys dementia a methiant y galon fel y rhai a allai fod angen gofal lliniarol, ond roedd pob un yn cynnwys canser
- Prin yw'r manylion yn y modelau o'r boblogaeth yn nhermau'r nodweddion a allai nodi'r rhai sydd angen gofal lliniarol
- Cafodd rhai modelau eu dilysu, ond nid ydym wedi asesu tryloywder y broses ddilysu
- Nid oedd unrhyw fodelau o'r boblogaeth yn edrych ar y math o ofynion gofal unigol na phryd y gallai fod ei angen. Fodd bynnag, mae'n bosibl bod y wybodaeth hon ar gael mewn offer sy'n nodi angen unigol am ofal lliniarol, ond ni wnaethom asesu'r rhain
- Nododd yr astudiaethau sylfaenol y nodweddion canlynol sy'n disgrifio'r rhai a allai fod angen gofal lliniarol:
 - oedran
 - cyd-afiachedd/aml-afiachedd (a ddisgrifir weithiau fel y rhai sy'n gysylltiedig ag angen gofal lliniarol yn unig)
 - grŵp afiechyd neu faich anabledd
 - lefel addysgol
 - ethnigrwydd
 - cenedl neu ryw
 - rhanbarth daearyddol
 - y defnydd o ofal iechyd a gofal cymdeithasol (ymweliadau â meddyg teulu, derbyniadau mewn adrannau Achosion Brys, derbyniadau cleifion mewnol, oriau iechyd cartref)
 - dewis iaith
 - baich poen
 - man preswyllo (cartref, cyfleuster gofal)
 - statws economaidd-gymdeithasol/anfantaais gymdeithasol (incwm blynyddol yr aelwyd fel arfer)



2. Modelau i nodi'r angen am ofal lliniarol a ragwelir yn y boblogaeth

Nodwyd saith model i ragweld yr angen am ofal diwedd oes a gofal lliniarol ar lefel y boblogaeth, gyda'r modelau mwy diweddar yn datblygu o'u rhagflaenwyr cronolegol. Mae'r mwyafrif ohonynt yn defnyddio dull llinellol syml a data am farwolaethau a data marwolaethau o glefydau penodol er mwyn rhagweld anghenion gofal lliniarol. Y prif wahaniaethau rhwng y modelau yw'r meini prawf ar gyfer oedran ac afiechyd neu gyflwr pobl a allai elwa ar ofal lliniarol.

Datblygwyd un o'r modelau cynharaf gan Higginson (1997). Roedd y model hwn yn addasiad o ddull gweithredu Stevens a Raftery (1994) ar gyfer asesiadau o anghenion sy'n seiliedig ar epidemioleg. Roedd yn ystyried effeithiolrwydd gwasanaethau a modelau gofal presennol er mwyn triogli angen.

Datblygodd Rosenwax et al. (2005) y dull o ddefnyddio ystadegau arferol am farwolaethau ymhellach i ragweld yr angen am ofal lliniarol yn y boblogaeth. Bu iddynt ddatblygu tri amcangyfrif i benderfynu pwy allai elwa ar ofal lliniarol: Amcangyfrif lleiaf, canolig ac uchaf.

Fe ymgorfforodd Gomez-Batiste et al. (2012) ddatblygiadau mewn arfer gofal lliniarol a mireinio'r defnydd o ddata ar y nifer o bobl oedd yn byw gyda chlefydau cronig, pobl hŷn â plwrpatholeg, dementia a'r rhai sy'n byw mewn cartrefi gofal.

Fe wnaeth Murtaugh et al. (2014) fireinio dulliau blaenorol (Higginson 1997, Rosenwax et al. 2005 a Gomez-Batiste et al. 2012) a seilio amcangyfrifon o'r angen am ofal lliniarol yn y boblogaeth ar safbwyntiau panel arbenigol. Gan ddefnyddio codau ICD-10 wedi eu diweddarau, ynghyd ag achos marwolaeth ar gyfer grwpiau dethol o gyflyrau, fe wnaethant amcangyfrif yr angen posibl am ofal lliniarol. Roedd pedwar amcangyfrif yn penderfynu pwy allai elwa ar ofal lliniarol: amcangyfrif lleiaf, canolig isaf, canolig uwch ac uchaf.

Yn seiliedig ar ddulliau blaenorol ar sail diagnosis, cynhaliodd model Etkind et al. (2017) ddau ddadansoddiad gan ddefnyddio methodoleg a ddatblygwyd gan Gomez-Batiste et al. (2012) a ddilynodd y dull ar sail diagnosis a ddatblygwyd gan Murtaugh et al. (2014). Defnyddiwyd rhagdybiaethau clir ynghylch newidiadau mewn mynychder clefydau dros amser a rhagdybiaethau swyddogol am farwolaethau, i gyfrifo cyfrannau penodol o ran oedran a rhyw marwolaethau i amcangyfrif yr angen am ofal lliniarol yn y boblogaeth.

Defnyddiodd May et al. (2020) ddata marwolaethau o bob achos ynghyd â chodau ICD-10 a grwpiau a sefydlwyd gan Etkind et al. (2017). Roedd y model yn defnyddio tri amcangyfrif: cyfanswm nifer y marwolaethau o glefyd oedd yn gysylltiedig â'r angen am ofal lliniarol; nifer o bobl 50+ sy'n byw ac yn marw gyda chlefydau sy'n nodi'r angen am ofal lliniarol yn ôl oedran a rhyw; a baich anabledd, mynychder poen a'r defnydd o ofal iechyd ymhlith pobl 50+ sy'n byw ac yn marw gyda chlefydau sy'n dynodi'r angen am ofal lliniarol.



Mae Finucane et al. (2021) yn amcangyfrif yr angen am ofal lliniarol yn y dyfodol gan ddefnyddio dull modelu llinol i ddatblygu'r dull a sefydlwyd gan Etkind et al. (2017) trwy gynnal dadansoddiad ychwanegol i amcangyfrif yr angen am ofal lliniarol yn ôl grŵp oedran, achos marwolaethau yn ôl grŵp clefydau a chyfran y bobl sy'n marw gydag amlafiachedd sy'n gysylltiedig â chlefydau cynyddol uwch ar draws grwpiau clefydau gwahanol.

Roedd y rhan fwyaf o'r modelau yn defnyddio codau system y Dosbarthiad Rhyngwladol o Glefydau i nodi grwpiau clefydau. Mae'r rhain yn seiliedig ar y degfed argraffiad (ICD-10). Mae'r grwpiau clefydau a gynhwyswyd wedi eu seilio'n gyffredinol ar y codau ICD-10 a amlinellwyd ym model Rosenwax et al. (2005).

Roedd modelau dilynol yn ehangu ar y rhestr a'i hail-drefnu, gan ymgorffori'r newidiadau i'r codau ICD-10 neu gynnwys mwy o bobl a allai fod angen gofal lliniarol:

- Methiant organau (clefyd y galon, methiant y galon, clefyd anadlol is cronig, methiant anadlol, clefyd reno-fasgwlaidd, methiant yr arennau, clefyd yr iau)
- Dementia (Dementia, dementia fasgwlaidd, clefyd Alzheimer, heneidd-dra)
- Arall (clefyd Huntington, clefyd niwronau motor, clefyd Parkinson, parlys uwch-niwclear cynyddol, sglerosis ymledol, atroffi aml-system, strôc gwaedlifol, isgemig ac amhenodol, HIV)

3. Astudiaethau sy'n defnyddio modelau i ragweld anghenion gofal lliniarol ymhlith poblogaethau

Nodwyd saith astudiaeth cohort neu drawstoriadol o'r boblogaeth gan ddefnyddio'r modelau a nodwyd yn flaenorol i ragweld amcangyfrifon o anghenion gofal lliniarol yn y boblogaeth yn y dyfodol. Mae'r rhain wedi eu hamlinellu yn nhabl 2 a chawsant eu cynnal gan ddefnyddio data o Awstralia, Colombia, yr Almaen, Iwerddon a Lloegr. Roedd un astudiaeth yn cymharu anghenion a amcangyfrifwyd ar draws 12 gwlad yn yr Undeb Ewropeaidd a thu hwnt i'r UE.

O'r modelau a nodwyd, model Murtagh et al. (2014) a ddefnyddiwyd amlaf (Westley-Wise, 2021; Calvache et al., 2020; a Kane et al., 2015). Roedd tair astudiaeth yn cymharu modelau er mwyn mesur yr ystod o amcangyfrifon rhagamcanol gan ddefnyddio'r un set ddata (Morin et al., 2017; Scholten et al., 2016; a Jeba et al., 2021). Roedd dwy ohonynt yn cymharu modelau Rosenwax et al. (2005) a Murtagh et al. (2014) (Morin et al., 2017 a Scholten et al., 2016). Yn ogystal â'r rhain, defnyddiodd Morin et al. (2017) y model a ddatblygwyd gan Arsyllfa Genedlaethol Ffrainc ar ofal diwedd oes (ONFV) hefyd i amcangyfrif yr angen am ofal lliniarol mewn 12 gwlad yn yr UE a thu hwnt i'r UE. Mae'r model hwn yn defnyddio rhestr wedi ei haddasu o gyflyrau cronig a sefydlwyd gan yr Institut National de Santé Publique du Québec. Cafodd y rhai a nodwyd fel pobl a allai fod angen gofal lliniarol eu gosod mewn tri chategori 'trywydd diwedd oes', yn seiliedig ar achos sylfaenol marwolaeth a theipoleg a awgrymwyd gan Murray a'i gydweithwyr. Ni wnaethom nodi'r model hwn yn ein chwiliadau, ond caiff ei amlinellu mewn llyfr Ffrengig, sydd



ar gael ar-lein. Bu Jeba et al. (2021) yn cymharu amcangyfrifon a ragwelwyd gan fodelau Gomez, Etkind, a Murtagh i amcangyfrif y lefel o angen am ofal lliniarol yng nghanolbarth Swydd Gaerhirfryn. Nid oedd y cymhelliad ar gyfer defnyddio modelau lluosog i amcangyfrif angen am ofal lliniarol yn glir.

Roedd pob un o'r astudiaethau yn rhagweld cynnydd yn nifer y bobl fyddai'n marw o glefyd/glefydau sy'n gysylltiedig ag angen am ofal lliniarol. Roedd astudiaeth o boblogaeth yn yr Alban yn rhagweld cynnydd o rhwng 74% (2017) a 95% (2040) (Finucane et al., 2021). Dangosodd astudiaeth o boblogaeth yn Colombia (Calvache et al., 2020) gynnydd hefyd yn y niferoedd absoliwt o farwolaethau rhwng 2012 a 2016. O'r rhain, roedd y rhai oedd angen gofal lliniarol (a ddiffiniwyd fel neoplasm malaen, clefyd y galon a serebro-fasgwlaidd, clefyd yr arennau, clefyd yr iau, clefydau anadlol, clefydau niwroddirwyol, clefyd Alzheimer, dementia a henaint, a HIV/AIDS) yn cynyddu 61.2%, gydag ychydig dros 31% o'r rhain yn gysylltiedig â chanser.

4. Nodweddion a allai gynorthwyo i nodi'r rhai a allai elwa ar ofal lliniarol

Canfu ein chwiliad hefyd astudiaethau arsylwi oedd yn disgrifio nodweddion unigol y rhai sydd angen gofal lliniarol o ddata poblogaeth, fel yr amlinellir yn nhabl 3. Roedd y rhan fwyaf o'r astudiaethau a nodwyd yn disgrifio ystadegau disgrifiadol i ddisgrifio nodweddion y boblogaeth o bobl allai fod angen gofal lliniarol. Roedd y rhain yn cynnwys:

- o oed (wedi ei rannu'n grwpiau oedran gwahanol)
- o cyd-afiachedd/aml-afiachedd (a ddisgrifir weithiau fel y rhai sy'n gysylltiedig ag angen gofal lliniarol yn unig)
- o gwlad enedigol
- o grŵp afiechyd neu faich anabledd (gwahanol gategoriâu – a ddiffinnir fel arfer o achos sylfaenol marwolaeth)
- o lefel addysgol
- o ethnigrwydd
- o cenedl neu ryw
- o rhanbarth daearyddol
- o y defnydd o ofal iechyd a gofal cymdeithasol (ymweliadau â meddyg teulu, derbyniadau mewn adrannau Achosion Brys, derbyniadau cleifion mewnol, oriau iechyd cartref)
- o dewis iaith
- o baich poen
- o man preswyllo (cartref, cyfleuster gofal)
- o statws economaidd-gymdeithasol/anfantais gymdeithasol (incwm blynyddol yr aelwyd fel arfer)

Roedd chwe astudiaeth sylfaenol wedi defnyddio ystadegau dadansoddol i ymchwilio i nodweddion y boblogaeth o bobl oedd yn derbyn gofal lliniarol neu oedd



angen gofal lliniarol. Trafodir y rhain mewn mwy o fanylder isod yn ôl nodweddion. Ar gais y rhanddeiliaid, mae unrhyw nodweddion sydd â chysylltiad penodol â dementia neu fethiant y galon wedi eu hamlygu'n dywyll.

4.1. Grŵp Clefydau

Mae'r niferoedd a amcangyfrifir o farwolaethau'n amrywio'n helaeth yn ôl grŵp clefydau. Mae hyn yn debygol o fod o ganlyniad i'r categorïau o wahanol glefydau sy'n cael eu hystyried gan awduron a'r modelau a ddefnyddiwyd, yn ogystal â'r data sydd ar gael. Fodd bynnag, mae Etkind et al. (2017) yn pwysleisio bod newidiadau codio arferol mewn setiau data marwolaethau, newidiadau posibl yn y dyfodol i driniaethau meddygol neu ganlyniadau cleifion, yn ei gwneud yn anodd i'r modelau hyn amcangyfrif marwolaethau yn ôl clefydau penodol. Er gwaethaf yr heriau hyn, trafodir y wybodaeth ganlynol am grwpiau clefydau a'r angen am ofal lliniarol a'r defnydd o ofal lliniarol.

Roedd dosbarthiad niferoedd y bobl o fewn y grwpiau clefydau penodol oedd yn cyfrif am angen gofal lliniarol yn amrywio ar draws yr astudiaeth. Roedd y mwyafrif yn cytuno y byddai canser yn cyfrif am gyfran fawr o angen cynyddol am ofal lliniarol (Etkind et al., 2017; Finucane et al., 2021; Scholten et al., 2016;). Fodd bynnag, nodwyd **clefyd y galon** (cynnydd o rhwng 8.4% a 30.8% gan ddefnyddio dulliau Rosenwax a Murtagh yn y drefn honno [Scholten et al., 2016]) a **dementia** (cynnydd o 185% Finucane et al., 2021; Etkind et al., 2017) hefyd fel achos sylfaenol ar gyfer y cynnydd posibl yn y galw am ofal lliniarol.

Canfu pob astudiaeth mai pobl â chanser oedd fwyaf tebygol o ddefnyddio gofal lliniarol. Ymhlith y rhai fu'n ymchwilio, pobl â **methiant y galon** (aOR 0.58; 95% CI 0.47–0.72: Westley-Wise et al., 2022) (Rosenwax et al., 2016) a **dementia difrifol** (Beernaert et al., 2013) oedd lleiaf tebygol o ddefnyddio gofal lliniarol, o gymharu â grwpiau clefydau eraill, ac eithrio clefyd rhwystrol cronig yr ysgyfaint (COPD) mewn un astudiaeth (Beernaert et al., 2013). Fodd bynnag, yn aml roedd yna niferoedd bach o gleifion â chyflyrau clefydau penodol (er enghraifft COPD a methiant y galon) (Beernaert et al., 2013).

4.2. Aml-afiachedd

Mae amcangyfrifon yn awgrymu y disgwylir i aml-afiachedd sy'n gysylltiedig â'r angen am ofal lliniarol gynyddu. Canfu astudiaeth oedd yn rhagweld yr angen am ofal lliniarol yn yr Alban o 2017 i 2040, yn gyffredinol, bod 27.5% o'r holl farwolaethau yn 2017 yn cynnwys pobl ag aml-afiachedd (a ddiffinnir fel o leiaf dau glefyd sy'n gysylltiedig ag angen am ofal lliniarol o wahanol grwpiau clefydau). Rhagwelir y bydd nifer y bobl fydd yn marw o aml-afiachedd yn cynyddu 82% erbyn 2040 yn yr Alban, gan gynrychioli 43.5% o'r holl farwolaethau neu 45.6% o'r holl farwolaethau gofal lliniarol (Finucane et al., 2021). Rhagwelir y bydd cyfran y rhai sy'n marw ag aml-afiachedd yn cynyddu 60% (27.2% i 43.5%). Mae'r cynnydd yn



digwydd yn bennaf ymhlith grwpiau oedran hŷn. Os bydd y tueddiadau yn parhau, erbyn 2040, mae Finucane et al. (2021) yn rhagweld y bydd 52% o bobl 85 i 99 oed yn marw o ddau neu fwy o glefydau sy'n gysylltiedig â'r angen am ofal lliniarol o wahanol grwpiau clefydau.

4.3. Rhyw

Ymddengys bod consensws cyffredinol bod menywod, yn enwedig y rhai â chanser yn fwy tebygol o fod angen, yn ogystal â chael mynediad at wasanaethau PC o gymharu â dynion. Canfu astudiaeth yng Ngwlad Belg (Beernaert et al., 2013) bod cleifion canser benywaidd yn fwy tebygol o gael eu hatgyfeirio at wasanaethau gofal lliniarol o gymharu â'u cyfoedion gwrywaidd (OR 1.46, 95% CI 1.05 i 2.05). Yn yr un modd, nododd Morin et al. (2017) bod dynion yn llai tebygol o fod wedi marw o gyflyrau sy'n gysylltiedig â'r angen am ofal lliniarol, o gymharu â menywod (roedd OR yn amrywio o 0.86 i 0.94) mewn naw o'r 12 gwlad lle cynhaliwyd yr amcangyfrifon.

4.4. Oed

Mae'n ymddangos bod tueddiadau dosbarthiad oed y boblogaeth ac oed ar farwolaeth yn effeithio ar nifer y bobl y rhagwelir y byddant angen gofal lliniarol yn y dyfodol. Fodd bynnag, mae'r categorïau grwpiau oedran gwahanol ymhlith y modelau a'r astudiaethau yn ei gwneud yn anodd gwneud cymariaethau uniongyrchol. Roedd Etkind et al., (2017) yn amcangyfrif anghenion y boblogaeth yn y dyfodol yng Nghymru a Lloegr erbyn 2040. Roeddent yn dangos y bydd y rhai 85 oed ac yn hŷn fydd angen gofal lliniarol yn dyblu bron rhwng 2014 a 2040, o 38.0% o'r amcangyfrif o'r angen cyffredinol am ofal lliniarol i 56.0% o'r amcangyfrif o'r angen yn y drefn honno. Mae hyn yn cymharu â'r grwpiau oedran 0 i 44 a 45 i 64 lle bydd y nifer yr amcangyfrifir o bobl fydd yn marw sydd angen gofal lliniarol yn gostwng erbyn 2040, o gymharu â data 2014.

Canfuwyd bod oed yn ffactor ystadegol arwyddocaol yn nhermau mynediad at ofal lliniarol. Canfuwyd bod mynediad at ofal lliniarol isaf ymhlith y **rhai <65 oed (aOR 0.44; 95% CI 0.31 i 0.64)** ymhlith y boblogaeth o bobl a fu farw yn Awstralia, neu ymadawedigion (Westley-Wise et al., 2022).

Roedd Morin et al. (2017) yn amcangyfrif y gyfran o ymadawedigion allai fod angen gofal lliniarol ar draws 12 gwladwriaeth yn yr UE a thu hwnt i'r UE. Wrth gymhwyso'r tri amcangyfrif, canfuwyd bod oed yn gysylltiedig â siawns uwch o fod angen gofal lliniarol ar ddiwedd oes. Fodd bynnag, gan ddefnyddio amcangyfrif Rosenwax, roedd y rhai oedd yn marw ≥ 90 oed yn llai tebygol o fod wedi bod angen gofal lliniarol o gymharu â'r rhai sy'n marw yn 18–49 oed (OR 0.84, 95% CI 0.83 i 0.85).



Preswyliaid

Canfu data trawstoriadol bod cleifion â **methiant y galon (OR 3.33, 95% CI 1.07 i 10.43) a dementia (OR 1.75, 95% CI 1.02 to 2.99)** yn fwy tebygol o gael eu hatgyfeirio pan oeddent yn byw mewn cartref nyrsio o'u cymharu â'r rhai oedd yn byw gartref, er y canfuwyd y gwrthwyneb ar gyfer cleifion canser (Beernaert et al., 2013). Cymharodd Morin et al. (2017) dri dull amcangyfrif a nodwyd yn gyson bod y rhai oedd yn marw mewn cartref nyrsio (OR yn amrywio o 1.04 i 1.32) yn fwy tebygol o fod yn gysylltiedig ag angen gofal lliniarol o'u cymharu â'r rhai fu farw gartref. Roedd y rhai oedd yn marw yn yr ysbyty (OR yn amrywio o 0.72 i 0.81) ac mewn lleoliadau eraill (OR yn amrywio o 0.57 i 0.84) yn llai tebygol o fod yn gysylltiedig ag angen gofal lliniarol o'u cymharu â'r rhai fu farw gartref. Fodd bynnag, o'u cymharu â'r bobl fu farw mewn preswylfa breifat, roedd y rhai fu farw mewn cyfleuster gofal preswyl i bobl hŷn (aOR 0.3, 95% CI 0.2 i 0.3, $p < 0.001$), cyfleuster gofal (aOR 0.3, 95% CI 0.2 i 0.5, $p < 0.001$) a phreswylfa arall neu anhysbys (aOR 0.4, 95% CI 0.2 i 0.6, $p < 0.001$) yn llai tebygol o gael mynediad at ofal lliniarol (Rosenwax et al., 2016).

Yn yr un modd, nododd dadansoddiad is-grŵp a gyfyngwyd i bobl fu farw ond nid o ganser bod y rhai oedd yn byw mewn cyfleuster gofal (OR 0.4; 95% CI 0.3 i 0.4; $p < 0.001$) o'u cymharu â phreswylfa breifat yn gysylltiedig â llai o fynediad at ofal lliniarol arbenigol (Rosenwax et al., 2016).

Roedd byw mewn dinasoedd mawr yn gysylltiedig â siawns uwch o gael mynediad at ofal lliniarol arbenigol (Rosenwax et al., 2016).

4.5. Statws priodasol

Roedd y rhan fwyaf o'r astudiaethau yn edrych ar statws priodasol fel nodwedd ddisgrifiadol y rhai oedd angen gofal lliniarol, yn hytrach nag yn nhermau rhagweld angen neu fynediad. Fodd bynnag, canfu Rosenwax et al. (2016) fod cael partner yn gysylltiedig â siawns uwch o gael mynediad at ofal lliniarol arbenigol.

4.6. Statws economaidd-gymdeithasol

Gan ddiystyru achos marwolaethau, roedd cyfrannau uwch o bobl fu farw wedi cael mynediad at ofal lliniarol arbenigol os oeddent yn byw mewn ardaloedd economaidd-gymdeithasol uwch ar adeg eu marwolaeth (Rosenwax et al., 2016). Fodd bynnag, wrth addasu ar gyfer newidynnau cymdeithasol a demograffig a rhoi cyfrif am yr achos marwolaeth sylfaenol, nid oedd statws economaidd-gymdeithasol is bellach yn gysylltiedig â llai o fynediad at ofal lliniarol arbenigol (Rosenwax et al., 2016). Yn yr un modd, ni chanfu cymariaethau wedi eu haddasu unrhyw gyswllt arwyddocaol rhwng cwintelau statws economaidd-gymdeithasol ardaloedd (Westley-Wise et al., 2021).



Nododd ein chwiliadau adolygiad systematig yn ymchwilio i'r cysylltiadau rhwng mesurau sefyllfa economaidd-gymdeithasol a'r defnydd o ofal iechyd yn ystod blwyddyn olaf bywyd, gan gynnwys gofal lliniarol arbenigol². Canfu meta-ddadansoddiad o 112 o astudiaethau arsylwi ansawdd uchel i ganolig, o'u cymharu â phobl sy'n byw yn y cymdogaethau lleiaf difreintiedig, pobl oedd yn byw yn y cymdogaethau mwyaf difreintiedig oedd lleiaf tebygol o dderbyn gofal lliniarol arbenigol (OR 1.13, 95% CI 1.07-1.19, $p < 0.001$). Am bob cynnydd cwintel mewn amddifadedd ardal, roedd peidio â derbyn gofal lliniarol arbenigol yn fwy tebygol (OR 1.03, 95% CI 1.02-1.05, $p < 0.001$). O'u cymharu â'r bobl fwyaf dysgedig (cymwysterau neu flynyddoedd o addysg a gwblhawyd), roedd y pobl lleiaf dysgedig yn fwy tebygol o beidio derbyn gofal lliniarol arbenigol (OR 1.26, 95% CI 1.07-1.49, $p = 0.005$).

4.7. Poen

Mae cynnydd sydd wedi ei amcangyfrif ym mynychder poen ymhlith pobl 50 oed ac yn hŷn yn lwerddon sy'n byw ac yn marw gyda chlefyd sy'n arwydd o angen gofal lliniarol, yn awgrymu y rhagwelir y bydd baich poen yn cynyddu i 68% rhwng 2016 a 2046 (May et al., 2020).

Ymgorfforodd Etkind et al., (2017) fynychder poen mewn rhagamcanion o angen gofal lliniarol. Er y rhagwelir y bydd y rhagamcanion o niferoedd y bobl sy'n marw o ddementia yn uwch na chanser erbyn 2040, fe wnaethant nodi y byddai nifer y bobl â chanser a phoen (175,254) yn uwch na nifer y bobl â **dementia a phoen** (131,645).

4.8. Nodweddion Eraill

Ymhlith y nodweddion eraill a ddefnyddiwyd i ddisgrifio poblogaethau a allai fod angen gofal lliniarol roedd baich anabledd, y defnydd o ofal iechyd (May et al., 2020), dewis iaith a gwlad enedigol (Westley-Wise et al., 2021).

5. Amseriad mynediad at ofal lliniarol a'i hyd

Thema gyffredin yn yr astudiaethau oedd bod y rhai gafodd ddiagnosis o ganser wedi cael mynediad at ofal lliniarol yn gynharach ac am gyfnod hwy o'u cymharu â chyflyrau eraill yr ymchwiliwyd iddynt. Mewn astudiaeth ôl-weithredol o garfan, o blith y rhai gafodd fynediad at ofal lliniarol, roedd nifer y dyddiau y derbyniodd pobl ofal lliniarol yn ystod blwyddyn olaf eu bywyd yn amrywio o rhwng 5 a 25 diwrnod (Rosenwax et al., 2016). Roedd dosbarthiad amserol nifer y diwrnodau o ofal lliniarol arbenigol a gyrchwyd yn ystod blwyddyn olaf bywyd yn gogwyddo tuag at yr wythnosau cyn marwolaeth. Roedd mwy na 60% o gyfanswm y dyddiau o ofal lliniarol mewn ysbyty wedi digwydd yn y pedair wythnos cyn marwolaeth, er bod hyn yn amrywio yn ôl prif achos marwolaeth. Roedd gofal lliniarol yn yr ysbyty yn dechrau canolrif o 15 (IQR 6–44) diwrnod cyn marwolaeth i'r rhai fu farw o ganser,



44 (IQR 8–149) diwrnod ar gyfer clefyd niwronau motor ac 8 (IQR 4–22) diwrnod ar gyfer y rhai fu farw â methiant yr iau. Roedd pobl â chyflyrau eraill a achosodd eu marwolaeth wedi dechrau derbyn gofal lliniarol yn yr ysbyty tua 5-6 diwrnod cyn eu marwolaeth (Rosenwax et al., 2016). Cafwyd mynediad at ofal lliniarol yn y gymuned yn gynharach ym mlwyddyn olaf bywyd gyda dyddiad cychwyn canolrifol o 62 (IQR 26–137) diwrnod cyn marwolaeth o ganser, 192 (IQR 19–365) diwrnod ar gyfer clefyd Huntington a 86 (IQR 20–253) diwrnod ar gyfer clefyd niwronau motor. Ar gyfer y cyflyrau eraill, roedd y dyddiadau dechrau canolrifol yn amrywio o 6 (IQR 3–54) diwrnod ar gyfer clefyd Alzheimer a hyd at 43 (IQR 15–138) diwrnod ar gyfer COPD (Rosenwax, et al., 2016).

Mae astudiaeth yn seiliedig ar y boblogaeth, gan ddefnyddio data o bractisau meddygon teulu yng Ngwlad Belg, yn disgrifio'r gwahaniaeth o ran amllder ac amseriad atgyfeirio cleifion â COPD, methiant y galon, dementia a chanser at wasanaethau gofal lliniarol (Beernaert et al., 2013). O'r 2,405 o farwolaethau cofrestredig, nifer y dyddiau canolrifol rhwng atgyfeiriad a marwolaeth oedd 10 (COPD), **12 (methiant y galon)**, **14 (Dementia difrifol)** ac 20 (canser) (Beernaert et al., 2013). Ni chanfuwyd unrhyw gysylltiadau arwyddocaol yn y dadansoddiadau aml-amrywedd ar gyfer cleifion â COPD, na rhwng nodweddion demograffig-cymdeithasol ac amseriad dechrau gwasanaethau gofal lliniarol ar gyfer y pedwar grŵp o glefydau (Beernaert et al., 2013).

Yn yr un modd, canfu astudiaeth garfan yn seiliedig ar y boblogaeth o Ontario, Canada (Quinn, et al. 2021) fod gan gleifion sy'n marw o **ddementia** siawns is o ddechrau derbyn gofal lliniarol ar 91 diwrnod neu fwy (aOR 0.42; 95% CI, 0.40 i 0.45) a rhwng 31 a 90 diwrnod (aOR, 0.60; 95% CI, 0.57 i 0.62) o gymharu â dechrau ar 30 diwrnod neu lai cyn marwolaeth o'u cymharu â chleifion â chanser.

6. Y mathau o angen am Ofal Lliniarol ar gyfer Dementia a Chlefyd y Galon

Cynhaliwyd chwiliad ar wahân ar ôl i randdeiliaid wneud cais am ffocws ar ddementia a methiant y galon yn nhermau'r mathau o ofal lliniarol sydd eu hangen.

Roedd papur gan Crowther et al. (2013)¹ yn archwilio **Gofal Lliniarol mewn Dementia** ac mae'n amlygu canfyddiadau o astudiaeth fawr ledled y DU o ofalwyr anffurfiol pobl â dementia er mwyn archwilio beth yw penderfynyddion gofal ar gyfer pobl â dementia a'u gofalwyr teuluol. Nododd cyfweiliadau manwl gyda theuluoedd oedd yn gofalu am bobl â dementia fu farw fod marwolaethau wedi digwydd mewn llawer o wahanol amgylcheddau, e.e. ysbytai cyffredinol dosbarth, cartrefi gofal nyrsio a phreswyl ac yn y cartref teuluol. Dim ond pedwar atgyfeiriad a wnaed at wasanaethau arbenigol gofal lliniarol a diwedd oes ymhlith y sampl (n=40) ac i'r atgyfeiriadau hyn gael eu gwneud ar gyfer y rhai â diagnosis canser hysbys ac wedi ei gadarnhau. Roedd cleifion â diagnosis deuol o ganser a dementia yn fwy tebygol o gael eu hatgyfeirio at wasanaethau gofal lliniarol; fodd bynnag, nid oedd yn ymddangos bod diagnosis deuol o ddementia a salwch cronig arall sy'n cyfyngu ar fywyd yn ysgogi atgyfeiriad at wasanaethau gofal lliniarol arbenigol.



Canfu astudiaeth o'r boblogaeth gan ddefnyddio data gweinyddol (Alqahtani et al., 2019) o UDA, o'r 939,680 o gleifion a dderbyniwyd mewn ysbytai gyda **Methiant aciwt y Galon**, derbyniodd 1.2% ofal lliniarol yn ystod eu harhosiad yn yr ysbyty. Mewn dadansoddiad atchweliad logistaidd aml-amrywedd, y rhagfynegwyr cryfaf ar gyfer atgyfeiriad at ofal lliniarol oedd henaint (OR 14.17, 95% CI 9.53-21.09 ar gyfer oedran > 85, a OR 6.18, 95% CI 4.18-9.15 ar gyfer oedran 65-85 [oedran cyfeirio 18-40]), sioc cardiogenig (OR 6.17, 95% CI 5.15-7.40), methiant cronig yr arennau (OR 4.19, 95% CI 3.75-4.68), a chymorth anadlu mecanyddol (OR 2.49, 95% CI 1.85-3.35). Roedd lleiafrifoedd hiliol yn llai tebygol o dderbyn gofal lliniarol o'u cymharu â chleifion Cawcasaid, yn y drefn honno: (OR 0.56, 95% CI 0.49-0.64) ar gyfer Americanwyr Affricanaidd o'u cymharu â Chawcasaid, a (OR 0.53, 95% CI 0.43-0.65) ar gyfer pobl Sbaenaidd o'u cymharu â Chawcasaid. Gwelwyd gwahaniaethau daearyddol hefyd yn y defnydd o ofal lliniarol gyda defnydd uwch mewn ysbytai yn y Gorllewin (OR 1.59, 95% CI 1.38-1.83).

7. Nodi angen heb ei gyflawni

O'r tair astudiaeth a nododd angen heb ei gyflawni fel rhan o'u dadansoddiadau, gwnaethant hynny drwy gymharu niferoedd y bobl oedd wedi marw oedd â chyflyrau y nodwyd eu bod angen gofal lliniarol a'r rhai oedd wedi cael mynediad at ofal lliniarol (Calvache et al., 2020 a Westley-Wise et al., 2022, Szekendi M et al. 2016).

Nododd yr astudiaeth o Awstralia (Westley-Wise, 2022) angen gofal lliniarol heb ei gyflawni o 13.3% ymhlith y rhai fu farw yn yr ysbyty oedd angen gofal lliniarol mewn rhanbarth rhwng 2016 a 2017. Y cyfrannau uchaf o 'angen heb ei gyflawni' oedd y rhai fu farw â COPD (31.0%) a methiant y galon (26.3%). I'r gwrthwyneb, mae astudiaeth garfan ôl-weithredol yn cymharu newidiadau yn y gwasanaeth gofal lliniarol a gyflawnwyd o'u cymharu â nifer y cleifion a allai elwa ar wasanaethau o'r fath rhwng 2000-02 a 2009-10 (Rosenwax et al., 2016). Dim ond 14 % (n = 729) o'r rhai fu farw â chyflyrau nad oeddent yn ganser gafodd fynediad at ofal lliniarol arbenigol yn y garfan 2009-10. Fodd bynnag, roedd hyn yn cynrychioli cynnydd o 6.1 % (95 % CI 4.9-7.3) yn y gofal lliniarol arbenigol y cafwyd mynediad ato a adroddwyd ar gyfer yr un grŵp o ymadawedigion ddeng mlynedd yn gynharach.

Canfu dadansoddiad ôl-weithredol trawstoriadol aml-safle o 33 ysbyty yn UDA (Szekendi M et al. 2016) fod 19% o gleifion mewnol ar ddiwrnod cyffredinolrwydd pwynt wedi eu hystyried yn briodol ar gyfer atgyfeiriad gofal lliniarol, ond dim ond tua 39% o'r rhain a atgyfeiriwyd at wasanaethau gofal lliniarol. O'r cleifion oedd yn briodol ar gyfer atgyfeiriad, roedd gan bron 80% yswiriant gofal iechyd Medicare (57.3%) neu fasnachol (22.2%). Roedd y gyfran o gleifion sy'n derbyn atgyfeiriadau yn gymharol gyson ar draws y grwpiau oedran, ac eithrio cleifion 84 oed ac yn hŷn, a atgyfeiriwyd yn amlach. Roedd arferion atgyfeirio yn amrywio yn ôl rhanbarthau daearyddol yr U.D.



Roedd trydedd astudiaeth o Colombia (Calvache et al., 2020) yn cyferbynnu ardaloedd daearyddol lle mae angen gwasanaethau gofal lliniarol a gwasanaethau gofal lliniarol gwirioneddol a gynigir a sefydlwyd bod gwahaniaeth amlwg rhyngddynt.

8. Amrywiad o angen amcangyfrifedig rhwng modelau

Nododd astudiaeth oedd yn cymharu dau fodel gan ddefnyddio data o'r Almaen wahaniaethau mawr yn nhermau nifer y bobl a allai elwa ar ofal lliniarol (Scholten et al., 2016), gyda bron i ddwywaith cymaint o bobl wedi eu nodi yn y dull Murtagh (78.0% o'r holl farwolaethau) o'i gymharu â dull amcangyfrif lleiaf posibl Rosenwax (40.7% o'r holl farwolaethau). Mae astudiaethau'n awgrymu bod yr ystod eang o angen amcangyfrifedig rhwng y modelau yn fwyaf tebygol o adlewyrchu'r model a ddewiswyd a'r mathau o amodau sydd wedi eu cynnwys yn y cyfrifiad amcangyfrifedig. Er enghraifft, nid yw dull Rosenwax yn cynnwys strôc, clefydau isgemig cronig y galon, sglerosis ymledol, dementia heb fod yn Alzheimer a diabetes ac felly dywedir yn aml ei fod yn tanamcangyfrif yr angen gwirioneddol am ofal lliniarol (Morin et al., 2017). Yn ogystal, bydd nodweddion y boblogaeth megis oedran a dosbarthiad grwpiau clefydau yn effeithio ar amcangyfrifon rhagamcanol.

9. Cyfyngiadau ac ystyriaethau'r modelau

Mae'n bwysig nodi bod y nodweddion a amlygwyd yn yr adroddiad hwn wedi eu nodi o astudiaethau arsylwi sy'n disgrifio poblogaethau a allai elwa ar ofal lliniarol. Maent yn defnyddio gwahanol setiau data poblogaeth ac yn ystyried gwahanol grwpiau clefydau y gallai fod angen gofal lliniarol arnynt, yn ogystal â chategorïau grwpiau oedran amrywiol. Felly, ni ellir gwneud cymariaethau uniongyrchol. Mae unrhyw gyfrannau neu arwyddocâd ystadegol yn ymwneud â'r boblogaeth sy'n cael ei hastudio yn unig ac mae'n annhebygol o fod yn gyffredinol i boblogaeth Cymru. Fodd bynnag, gallent fod yn ddefnyddiol er mwyn pwysleisio nodweddion pwysig y rhai sydd angen gofal lliniarol, a fydd yn ddefnyddiol er mwyn hysbysu datblygiad asesiad o'r effaith ar anghenion ar gyfer gofal lliniarol yng Nghymru. Mae hefyd yn amlygu unrhyw nodweddion nad ydynt wedi eu harchwilio eto ymhlith pobl a allai fod angen gofal lliniarol ar lefel y boblogaeth.

Mae'r rhan fwyaf o astudiaethau hefyd yn rhybuddio am y posibilrwydd o danamcangyfrif yr angen am ofal lliniarol wrth ddefnyddio tystysgrifau marwolaeth. Tynnodd llawer o awduron achos sylfaenol y farwolaeth yn unig o'r tystysgrifau, sy'n atal y gallu i gynnal dadansoddiadau o achosion marwolaeth lluosog, gan arwain at danamcangyfrif amllder gwirioneddol y clefyd ac yn ei dro yr angen am ofal lliniarol. Gellir goresgyn hyn trwy ddefnyddio ffynonellau data ychwanegol (cronfeydd data gofal sylfaenol a chofnodion ysbytai).

Ffactor arall a amlygwyd yw bod amcangyfrifon yn cyfeirio at yr angen cyffredinol am ofal lliniarol, waeth beth yw lefel neu leoliad y gofal. Gallai modelau sy'n ymgorffori 'trywydd' helpu i ymgorffori angen cymhleth am ofal lliniarol ac anghenion gwahanol



grwpiau gwahanol o gleifion sy'n dioddef cyflyrau cronig ar ddiwedd bywyd (Morin et al., 2017).

Noder, ni chynhaliwyd unrhyw werthusiad ansawdd felly ni all y Gwasanaeth Tystiolaeth roi sylwadau ar ansawdd methodolegol y ffynonellau a nodir yn unrhyw rai o'r tablau. Os bydd unrhyw bapur i'w ddefnyddio ar gyfer ystyriaethau polisi, dylid cynnal asesiad ansawdd ac ystyried cyffredinolli canfyddiadau i'ch cyd-destun chi.

- Ble wnaethoch chi chwilio?**

Cynyddwyd y gwaith o ganfod ffynonellau eilaidd yn ogystal â'r ffynonellau isod.

Resource	Success or relevancy of the retrieval
Cochrane Library (basic search) https://www.cochranelibrary.com/cdsr/reviews	Searched, results found
NICE (basic search) https://www.nice.org.uk/guidance	Searched, results found
Medline (basic search) https://dialog.proquest.com/professional/medlineprof?accountid=16678	Searched, results found
Google Scholar (basic search) https://scholar.google.com/	Searched, results found
Scottish Intercollegiate Guidelines Network (SIGN) clinical guidelines (basic search) https://www.sign.ac.uk/our-guidelines	Searched, results found
Agency for Healthcare Research and Quality (AHRQ) (basic search) https://www.ahrq.gov/research/findings/evidence-based-reports/search.html	Searched, results found
Canadian Agency for Drugs and Technologies in Health (CADTH) (basic search) https://www.cadth.ca/	Searched, results found
US Department of Veteran Affairs (basic search) https://www.hsrd.research.va.gov/publications/esp/reports.cfm	Searched, results found
National Institute for Health Research (NIHR) Health Technology Assessment (HTA) Journal (basic search) https://www.journalslibrary.nihr.ac.uk/hta/#/	Searched, nothing found
National Institute for Health Research (NIHR) Public Health Research (basic search) https://www.journalslibrary.nihr.ac.uk/phr/#/	Searched, nothing found
Campbell Collaboration systematic reviews (basic search) https://www.campbellcollaboration.org/better-evidence.html	Searched, nothing found



The Community Guide (basic search) https://www.thecommunityguide.org/publications	Searched, nothing found
Evidence for Policy and Practice Information and Co-ordination Centre (basic search) http://eppi.ioe.ac.uk/cms/Default.aspx?tabid=62	Searched, results found
Joanna Briggs Institute (basic search) https://journals.lww.com/jbisrir/Pages/default.aspx	Searched, results found
What Works Centre for Wellbeing (basic search) https://whatworkswellbeing.org/resources/	Searched, nothing found

- **Pa dermau wnaethoch chi eu defnyddio?**

Cynhaliwyd chwiliad cychwynnol gan ddefnyddio cyfuniad o'r termau canlynol:

- gofal lliniarol
- gofal diwedd oes
- asesiad o anghenion y boblogaeth
- dangosyddion

- **Data a Ddyfynnwyd o lenyddiaeth a nodwyd**

Tabl 1: Modelau a nodwyd i amcangyfrif y lefel o anghenion gofal lliniarol ar lefel y boblogaeth

Higginson (1997). Health care needs assessment: palliative and terminal care. In: Stevens A, Raftery J, eds. Health care needs assessment: The epidemiologically based needs reviews. Oxford: Radcliffe Medical Press, 1997, pp. 1e45.

Available from: This paper is not available

Higginson (1997) developed one of the earliest models for population needs assessment for palliative care (PC). This model was adapted from the approach developed by Stevens and Raftery (1994) for epidemiologically based needs assessment.

Model outline: Using the number of people with selected causes of deaths (cancer and six selected non-cancer disease groups) multiplied by standard symptom prevalence (separately for cancer and non-cancer patients), this model triangulates three sources of information:

1. The size of the need i.e. the incidence and prevalence: For each of the subcategories, estimate incidence and prevalence figures and calculate likely need using data on death rates (number of patients at the end of life and number of families affected) and symptoms experienced (pain, breathlessness, depression). This can be made more detailed by using data on local populations (e.g., local death rates, standardized mortality ratios, deprivation index, ethnic composition, trends).
2. The services available locally, and
3. The effectiveness and cost-effectiveness of potential services

This model estimated PC need in the UK. It estimates that about 2,800 people per 1,000,000 population die from cancer each year in the UK; 25–65% of these will need help from a PC support team, and 15–25% will need inpatient hospice care. About 6,900 people per 1,000,000 population die from causes other than cancer each year, and although some of these people will die suddenly or with no identifiable terminal period, many will have circulatory, respiratory or neurological diseases with prevalence of symptoms comparable to that suffered by cancer patients.

Disease groups considered in need of PC: 1) All cancer deaths, and 2) Non-cancer deaths from diseases of: circulatory system, respiratory system, chronic liver and cirrhosis, nervous system and sense organs (including Parkinson's disease, multiple sclerosis and meningitis), senile and pre-senile conditions, and endocrine, nutritional, metabolic and immunity disease.

Data input into the model: 1) Disease-specific mortality, and 2) Standard symptom prevalence in relevant diseases (systematic review).

Characteristics that may identify those in need of PC: unable to access original paper

Considerations: The model uses prevalence of different symptoms (pain, breathlessness, depression) that overlap; therefore, it is difficult to get a precise number of PC need. Compared to its successors, it includes a limited number of non-cancer conditions requiring PC.

Rosenwax et al. (2005). Estimating the size of a potential palliative care population. *Palliative Medicine*. 19(7): pp.556-562.

Available from: <https://pubmed.ncbi.nlm.nih.gov/16295289/>

Rosenwax et al. (2005) developed a model that further developed the method of using routine mortality statistics to estimate the need for cancer and non-cancer PC in a population, using all deaths from any of 10 specific disease groups.

Model outline: This model produced three estimates to determine who could benefit from PC through focus groups, interviews and a literature review:

1. Minimal estimate: A conservative measure based on the number of deaths from 10 specific disease groups
2. Mid-range estimate: Included all deaths hospitalised with the same condition as certified on the death certificate sometime in the year before death, and
3. Maximal estimate: A broad measure that includes all deaths apart from poisoning, injury, and maternal, neonatal or perinatal deaths.

The three estimation models were applied to a cohort of people who died in Western Australia between 1 July 2000 and 31 December 2002 using disease specific mortality by linking death records with hospital morbidity data through the Western Australian Data Linkage System. The model demonstrated that between 0.28% and 0.50% of people in the Western Australian population in any one year could potentially benefit from a PC approach, some of whom would benefit from specialist PC services. The Minimal Estimate identified that 50.0% of all deaths in Western Australia in the 2.5-year period could have benefited from PC. While the Mid-range and Maximal Estimate identified 55.5% and 89.4% of all deaths could have benefited from PC. Most people in the PC constituency (irrespective of the estimate used) were aged 65 years and older (78.8%, 79.6% to 81.6%), non-Aboriginal (93.2%, 93.4% to 93.8%), married (48.8%,

48.0% to 43.4%) or widowed (33.2%, 34.1% to 38.0%), living in the major cities of Western Australia (71.0%, 70.6% to 71.7%) and about one third were socioeconomically disadvantaged.

Disease groups considered in need of PC:

1. For the Minimal and Mid-range Estimate: All cancer deaths (malignant and benign neoplasm), and Non cancer deaths including Heart failure, Renal failure, Liver failure, Chronic obstructive pulmonary disease, Motor Neuron Disease, Parkinson's disease, Huntington's disease, Alzheimer's disease and HIV/AIDS.
2. For the Maximal Estimate: All deaths (except deaths during pregnancy, childbirth, or puerperium; originating during the perinatal period; or resulting from injury, poisoning, and certain other external causes; or resulting from external causes of morbidity and mortality).

Data input into the model: 1) Mortality register and health service data using Western Australian Data Linkage System and 2) The Index of Socio-Economic Disadvantage (IRSD) derived from Census of Population and Housing and 3) the Accessibility Remoteness Index of Australia was attached to the database using the Australian Bureau of Statistics collector's district.

Characteristics that may identify those in need of PC: age groups (<65 years and 65 and over), ethnicity, marital status, place of residence, socioeconomical position – descriptive statistics only

Considerations: The Minimal Estimate is condition-based rather than needs-based and includes only a limited number of conditions as an indicator of PC need. The Mid-range and Maximal Estimate are partially needs-based. The Maximal Estimate could be regarded as the ideal state of affairs as it represents a world where PC is so ubiquitous and well understood by healthcare workers and the community alike that all patients have access to PC. However, in reality this might not occur for a variety of reasons: sociocultural factors, attitudes to death and dying, ignorance of PC, financial constraints and historical patterns of providing care. To address this, a more moderate, needs-based constituency was developed, the Mid-range Estimate, that represents the population who were hospitalised in the last 12 months of life for a condition from which they died. This includes patients who are already in contact with healthcare services and whose doctors are alerted to the possibility that their conditions are, at least potentially, life-threatening. PC should, therefore, be more readily accessible to these patients than those in the Maximal Estimate.

Gómez-Batiste et al. (2012). Identifying needs and improving palliative care of chronically ill patients: a community-oriented, population-based, public-health approach. Current opinion in supportive and palliative care. 6(3): pp.371-378.

This model was first published in a Portuguese paper in 2010. Unfortunately, we could not locate a translation of this and the majority of subsequent references to this model refer to the paper above from 2012.

Available from: <https://pubmed.ncbi.nlm.nih.gov/22801465/>

Model outline: To address limitations identified in previous models (Higginson;1997 and Rosenwax et al.;2005), this model incorporated developments in PC practice and refined the use of data on the prevalence of advanced chronic disease, older people with pluripathology, dementia and care home residence.

In a worked example in Catalonia, this model estimated that 75% of all deaths were from chronic progressive diseases while proposing consideration of prevalence of chronic diseases, dementia and nursing home patients to further refine this. In developed countries with ageing populations (15–20% >65 years of age) and annual mortality levels of 9 deaths per 1000, this model estimated 60–75% of the population will die as a result of a chronic advanced progressive illness that includes a period of terminal illness. The most frequent causes are: cancer (20–25%), chronic organ failure (cardiac, pulmonary, hepatic and renal), neurological diseases, HIV/AIDS and other infectious conditions (35–45%)

Disease groups considered in need of PC:

- 1) All cause deaths
- 2) Patients living with advanced chronic disease and limited life prognosis
- 3) Elderly (≥ 65 years) with: pluripathology and dependency
- 4) Elderly (≥ 65 years) with dementia, and
- 5) Elderly (≥ 65 years) living in nursing homes or homes for the elderly

Data input into the model: 1) Total (all-cause) mortality and 2) Prevalence of disease, dependency, multiple pathology, symptom and housing data

Characteristics that may identify those in need of PC: unable to access original paper

Considerations: unable to access original paper

Murtagh et al. (2014). How many people need palliative care? A study developing and comparing methods for population-based estimates. Palliative Medicine. 28(1): pp.49-58.

Available from: <https://pubmed.ncbi.nlm.nih.gov/23695827/>

Model: This model was developed as a refinement to existing methods (Higginson 1997, Rosenwax et al. 2005 and Gomez-Batiste et al. 2012) incorporating the views of an expert panel. The expert panel review identified changing practice (e.g. extension of palliative care to more non-cancer conditions), changing patterns of hospital/home care and multiple, rather than single, causes of death as important. This led to updating the list of ICD-10 causes of death used to estimate need of PC. The model used the number of people with selected underlying cause of death (updated to current practice) plus contributing cause of death for selected groups of conditions to estimate co-morbidities. Four estimates were developed to determine who could benefit from PC:

- 1) Minimal Estimate: Based on the number of deaths from specific conditions.
- 2) Lower mid-range estimate: Extends the Low Estimate of Rosenwax to also include cases admitted to hospital in the year before death with the same condition as documented as 'cause of death', in addition to deaths where Alzheimer's, dementia, senility or chronic renal failure is recorded as a contributory cause (to further identify these specifically under-reported diseases),
- 3) Upper mid-range Estimate: Includes all deaths with any mention on the death certificate (underlying or contributory) of the disease categories used for the minimum estimate, and
- 4) Maximal Estimate: As per Rosenwax et al. (2005) Maximal Estimate.

Application of the four-estimation model to mortality data for England for the period of 2006 to 2008 estimated between 297,985 and 456,767 people needed PC annually during this period. This represents between 63.03% (95% CI 62.95% to 63.11%) using the Minimal Estimate and 96.61% (95% CI 96.58% to 96.64%) using the Maximal Estimate of all deaths during this period.

Disease groups considered in need of PC:

- 1) All cancer deaths- malignant neoplasms only included, and
- 2) Non cancer disease groups:
 - (i) Organ failure (heart disease, heart failure, chronic lower respiratory disease, respiratory failure, reno-vascular disease, renal failure, liver disease)
 - (ii) Dementia (Dementia, vascular dementia, Alzheimer's disease, senility) and
 - (iii) Other (Huntington's disease, motor neurone disease, Parkinson's disease, progressive supra-nuclear palsy, multiple sclerosis, multi-system atrophy; haemorrhagic, ischaemic and unspecified stroke; HIV)

Data input into the model: 1) Office for National Statistics (ONS) mortality data, and 2) Linked hospital admissions data from Hospital Episode Statistics (HES).

Characteristics that may identify those in need of PC: Age

Consideration: Cause of death, while indicative of potential PC need, is not a precise indicator of PC or an accurate reflection of diagnosis as certain conditions can be under-recorded. The model allows for the latter by including both the contributory cause of death and the underlying cause of death in the mid-range estimates. Estimating PC need through the number of deaths does not reflect the trajectory of those needs prior to death; this may be particularly relevant for children and young people, where the overall numbers of deaths were small but the trajectory of PC needs for some conditions may extend over several years. Subject to limitations caused by under-reporting on death certificates. All the refined estimates (minimal, mid-range and maximal) can be derived for local and regional populations, using readily available data, thus allowing commissioners to estimate how many people need palliative care in their Clinical Commissioning group area and commission accordingly.

Etkind et al. (2017). How many people will need palliative care in 2040? Past trends, future projections and implications for services. BMC Medicine. 15(102).

Available from: <https://bmcmmedicine.biomedcentral.com/articles/10.1186/s12916-017-0860-2>

Model outline: This model was developed to estimate future trends in PC need using routinely available national death registry data and mortality projections. Etkind et al. estimated and projected PC need using two analyses:

1. Based on the method used by Gomez-Batiste et al. (2012), assuming that 75% of people in high-income countries die with PC needs. Projected PC need therefore is calculated as 75% of projected deaths annually to a future date, assuming the proportion of deaths requiring palliative care would remain constant.
2. This method uses a diagnosis-based estimate and models two scenarios:
 - a. Assuming proportion of PC need stays constant: Calculate the number and proportion of age and sex-specific deaths where an ICD-10 code associated with PC was recorded as the main underlying cause of death only, then apply this proportion to projected mortality forecasts for each year, with no adjustments.
 - b. Assuming an annual change: Calculate the mean annual change in the proportion of deaths requiring PC in a given period, assuming the annual change would continue to occur in a linear fashion, and then apply this proportion to projected mortality forecasts.

To project PC need by age and disease-specific group, changes in PC need in specific age and disease groups are investigated by describing the number of people in each 5-year age group who are projected to need PC between the forecast timeframe, and then undertake disease group-specific projections.

This model was used to estimate future population PC needs in England and Wales by 2040. The model estimated that if the age- and sex-specific proportions with PC needs remain the same as in 2014, the number of people requiring PC will grow by 25.0% (from 375,398 to 469,305 people/year). However, if the upward trend observed from 2006 to 2014 continues, the increase will be 42.4% (161,842 more people/year, total 537,240 people/year). Additionally, the disease-specific projections show that dementia and cancer will account for the predominant growth in PC need.

To assess the robustness of their methodology, the authors undertook sensitivity analyses. Firstly, they adjusted for the time period over which death registry and mortality projections data were collected and assessed the effect this had on their projections by comparing whether the PC estimate reached using 2014–2015 population data with 2014 death registry data, was the same estimate using 2013–2014 population data with 2014 death registry data. They found that using the later period reduced the PC need estimate by 0.5%. Secondly, they applied the Lee–Carter approach to mortality projections to produce an alternative projection and compared this to their main methodology and found that 551,146 people would need palliative care by 2040. This differs by 2.6% from their projection of 537,240 using method 2 (assuming annual change 2006–2014).

Disease groups considered in need of PC:

1) All cancer deaths- malignant neoplasms only included, and 2) Non cancer disease groups:

- (i) Organ failure (Heart disease, heart failure, chronic lower respiratory disease, respiratory failure, reno-vascular disease, renal failure, liver disease);
- (ii) Dementia (Dementia, vascular dementia, Alzheimer's disease, senility); and
- (iii) Other (Huntington's disease, motor neurone disease, Parkinson's disease, progressive supra-nuclear palsy, multiple sclerosis, multi-system atrophy; haemorrhagic, ischaemic and unspecified stroke; HIV).

Data input into the model: Total (all-cause) mortality from ONS death registry data, population data from ONS using a mid-year estimate on June 30th.

Characteristics that may identify those in need of PC: age groups (0-44, 45-64, 65-74, 75-84, 85 years and over), sex, disease group (Cancer, organ failure, dementia, other deaths)

Considerations: The aggregate model uses recent trends to project future levels of need, because of this, it cannot account for potential future changes in medical treatments or patient outcomes. These estimates do not account for multi-morbidity as based on cause-of death. Use of death registry data means that this model can only estimate PC need at the end of life. Whilst the majority of PC needs do occur in the last months of life, PC needs are increasingly recognised earlier in the disease course, and such needs would not be captured by these estimates. This model used the methodology developed by Gomez-Batiste et al. (2012); therefore, it is subject to limitations inherent to the original model.

May et al. (2020). Population-based palliative care planning in Ireland: how many people will live and die with serious illness to 2046? HRB Open Research, 2.

Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7017420/>

Model outline: This model was developed to extrapolate future trends in PC need using static modelling of routinely available national death registry data and mortality projections. May et al. estimated and projected PC need using three analyses:

1. This projection methodology models four scenarios:
 - a. Based on the method used by Gomez-Batiste et al. (2012), assuming that 75% of people in high-income countries die with PC needs, projected PC need is calculated as 75% of projected deaths annually to a future date.
 - b. Assuming proportion of PC need stays constant: Calculate the number and proportion of deaths for a year where an ICD-10 code associated with PC was recorded as the main underlying cause of death only, and then apply this proportion to mortality forecasts for each year up to a future date, with no adjustments.
 - c. Assuming an annual change, prior 8 years: Calculate the mean annual change in the proportion of deaths requiring PC in an 8-year period, assuming the increases according to a compound interest rate, then applied this proportion to mortality forecasts up to a future date.
 - d. Assuming an annual change, prior 3 years: Calculate the mean annual change in the proportion of deaths requiring PC in a 3-year period, assuming the increases according to a compound interest rate, then applied this proportion to mortality forecasts up to a future date.
 - e. Assuming annual change, by age and gender: Calculate the number and proportion of age and gender-specific deaths in a year where an ICD-10 code associated with PC was recorded as the main underlying cause of death only. Assuming the increases according to a compound interest rate by gender for each five-year age band, then applied this proportion to mortality forecasts up to a future date.
2. This method estimated the number of people aged 50+ living and dying with diseases indicating PC need, by age and gender, for a future period. For each projected year, the number of people projected to live through the year was multiplied by the proportion of people living with a disease indicating PC need, as well as multiplying the number of people projected to die by the proportion of people dying with a disease indicating PC need.
3. This method estimated the disability burden, pain prevalence and health care utilisation among people aged 50+ living and dying with diseases indicating PC need for a future period. For each outcome of interest (disability burden, pain prevalence, utilisation categories), calculate the mean, adjusted for age, gender and PC disease, among people aged 50+. Combine these calculations with the population projections from Analysis 2. To quantify growth in disability and pain burden, and use of different health care services, in a single comprehensible index values were set in each outcome for the first year of the forecast to 100. Indices for

the forecast period were then created with the set value as a base (e.g. a 50% increase in any outcome to 2046 gives a 2046 score of 150, etc.). Health service utilisation was based on current patterns, implicitly assuming no changes in policy or access during the projection period.

This model estimated PC need in the Republic of Ireland from 2016 to 2046. Using the assumption of constant need, it estimated a 68% increase in the total number of deaths from a disease associated with PC from 2016 to 2046. Using the changing needs methods, increase in absolute numbers of deaths from a disease associated with PC need between were estimated to be between 78% and 84%. The model projected an increase of 74% in number of people aged 50+ dying annually with a PC need and an increase of 89% in the number of people aged 50+ living through the year with a PC need. It also estimated increases in healthcare outcomes for older people living through the year with a disease indicating PC need between 2016 and 2046: 173% for disability burden, 83% for pain burden; and health care use: GP visits (101%), emergency department admissions (90%), inpatient hospital admissions (100%) and home health hours (106%). It estimated increases in outcomes for older people dying with a disease indicating PC need: 96% for disability burden, 68% for pain burden; and health care use: GP visits (74%), emergency department admissions (65%), inpatient hospital admissions (62%) and home health hours (107%).

Disease groups considered in need of PC:

- 1) All cancer deaths- malignant neoplasms only included, and 2) Non cancer disease groups:
 - a. Organ failure (Heart disease, heart failure, chronic lower respiratory disease, respiratory failure, reno-vascular disease, renal failure, liver disease);
 - b. Dementia (Dementia, vascular dementia, Alzheimer's disease, senility); and
 - c. Other (Huntington's disease, motor neurone disease, Parkinson's disease, progressive supra-nuclear palsy, multiple sclerosis, multi-system atrophy; haemorrhagic, ischaemic and unspecified stroke; HIV).

Data input into the model: 1) Total (all-cause) mortality from Central Statistics Office (CSO) in Ireland; 2) mortality by age and gender from CSO in Ireland; and 3) data from The Irish Longitudinal study on Ageing (TILDA) for participants living with a disease indicating PC need.

Characteristics that may identify those in need of PC: Age group, gender, co-morbidities, disability burden, pain burden, health and social care utilisation (GP visits, ED admissions, inpatient admissions, home health hours)- descriptive stats only

Considerations: Static modelling assumes no change in disease profile by age and gender. This model assumed no exogenous changes in outcomes while making the projections. The healthcare use estimation is based on past use and not need, so unmet need may be uncounted while unnecessary use may be over-counted. Dynamic modelling that takes account of the interaction of different variables over time, as well as cross-validating predictive accuracy and quantifying the uncertainty associated with all stages of projections, would

offer a more sophisticated picture of future population numbers and their associated outcomes. Use of death registry data relies on accurate completion of death certificates. Data used from TILDA is subject to self-report bias. TILDA does not specifically ask about all causes of deaths used in this model. Therefore, the authors reviewed the CSO cause-of-death data, counting only diseases recorded by TILDA, and found a 1% discrepancy. This model used the methodology developed by Etkind et al. (2017); therefore, it is subject to limitations of the original model.

Finucane et al. (2021). How many people will need palliative care in Scotland by 2040? A mixed-method study of projected palliative care need and recommendations for service delivery. *BMJ open*. 11(2): pp.e041317.

Available from: <https://bmjopen.bmj.com/content/11/2/e041317>

Model outline: This model was developed to provide a more comprehensive picture of future palliative care need than previous models, using simple linear modelling of routinely available national death registry data and mortality projections. Finucane et al. estimated and projected PC need using three approaches:

1. Based on the method used by Gomez-Batiste et al. (2012), assuming that 75% of people in high-income countries die with PC needs, projected PC need is calculated as 75% of projected deaths annually to a future date.
2. This estimation methods takes a diagnosis-based approach, replicating scenarios used by Etkind et al. (2017):
 - a. Assuming proportion of PC needs constant: Calculate the number and proportion of age and gender-specific deaths at baseline where an ICD-10 code associated with PC was recorded as the main underlying cause of death only, and then apply this proportion to mortality forecasts for each year up to a future date, with no adjustments.
 - b. Assuming an annual change: Calculate the mean annual change in the proportion of deaths requiring PC for a past period of time, assuming the mean annual change to be linear. Apply the resulting proportion to mortality forecasts up to a future date.
3. Builds on the diagnosis-based approach by using the number of people for whom a PC relevant disease was recorded as the main underlying cause as well as a contributory cause of death. Finucane et al. predict this to be the most accurate and comprehensive estimate of deaths in a calendar year. To project future need, calculate the number and proportion of age and gender-specific deaths where an ICD-10 code associated with PC care is recorded as either the main underlying or contributory cause of death. Assuming the mean annual change in the proportion of deaths associated with PC need over the baseline continues to occur in a linear fashion, apply the resulting mean annual change to mortality forecasts.

This model was applied to estimate PC need in Scotland from 2007 to 2017. During the 11-year period, registered deaths rose by 3.4% in Scotland. Using all methods to estimate population level palliative care need, estimations of the number of people who died with PC needs in Scotland in 2017 ranged from 43,403 (method 1) to 52,148 (method 3), an increase from 2007 irrespective of method used.

Mortality projections to 2040 indicate a 13.6% increase of deaths in Scotland. Models estimated between 75% and 95% of those who die by 2040 might benefit from a PC approach. Authors also projected PC need by age group, underlying cause of death and multi-morbidity associated with advanced progressive disease up to 2040 using method 2B.

Disease groups considered in need of PC:

- 1) All cancer deaths- malignant neoplasms only included, and 2) Non cancer disease groups:
 - a. Organ failure (heart disease, heart failure, chronic lower respiratory disease, respiratory failure, reno-vascular disease, renal failure, liver disease)
 - b. Dementia (Dementia, vascular dementia, Alzheimer's disease, senility) and
 - c. Other (Huntington's disease, motor neurone disease, Parkinson's disease, progressive supra-nuclear palsy, multiple sclerosis, multi-system atrophy; haemorrhagic, ischaemic and unspecified stroke; HIV).

Data input into the model: 1) National death registry data from National Records of Scotland, and 2) Official mortality forecasts from Office for National Statistics and National Records of Scotland

Characteristics that may identify those in need of PC: age group (0-44, 45-64, 65-74, 75-85, 85-99, 100+), underlying cause of death (cancer, organ failure, dementia, neurological/stroke/HIV), multi-morbidity (diseases associated with PC need in the four categories) – descriptive statistics only

Considerations: Linear models presume projections will occur at the same rate as recent trends, and do not account for variability. Authors used a disease count approach to estimate multi-morbidity relevant to population palliative care need, as this is straightforward to estimate and replicate. Definition of multi-morbidity was relatively restrictive—decedents were required to have two major illnesses from different disease groups, both of which would individually confer PC need. These models draw on trends over an 11-year period, up to and including 2017, and project these trends forward. Similar to its predecessors, this model uses death registry data that relies on accurate completion of death certificates. Changes in how cause of death is recorded over time cannot be accounted for, though previous changes have had minor impact on population level coding. In addition, estimates make no adjustments for pandemic events, such as COVID-19 which have particularly affected people aged 75 and over. It is likely age-specific mortality rates are likely to change as a result of this. This model used the methodology developed by Etkind et al. (2017); therefore, it is subject to limitations of the original model.

Tabl 2: Astudiaethau a ddefnyddiodd y modelau a nodwyd yn nhabl 1

Westley-Wise et al. (2022) Who needs, receives and misses out on palliative and end-of-life care? A population-based study to identify needs and gaps in a regional health service. *Australian Health Review*.

Available from: <https://www.publish.csiro.au/AH/AH21052>

Model(s) tested: Murtagh et al. (2014)

Summary: This cross-sectional descriptive and analytical study aimed to assess the unmet need for palliative and end of life care, as well as sociodemographic and diagnostic factors associated with suboptimal access, among residents in an Australian region.

It estimated that from a population of 3175 patients aged 15+ who died in hospital in the region in 2016 and 2017, 74.8% needed palliative or end-of-life care in the year before death. Approximately 13.3% did not receive any. The highest proportions of 'unmet need' were in decedents with COPD (31.0%) and heart failure (26.3%).

Adjusting for sociodemographic and diagnostic factors, access was lowest among those aged <65 years (aOR 0.44; 95% CI 0.31–0.64) and those with heart failure (aOR 0.58; 95% CI 0.47–0.72).

Data collection: Data was collected from a databank established by the Centre for Health Research Illawarra Shoalhaven Population using six datasets; admitted patients (AP), sub- and non-acute in-patients (SNAP), emergency department (ED), non-admitted patients (NAP), death audit (DA)16 and regional Palliative Care Outcomes Collaboration (PCOC), Death data was coded according to ICD-10 codes and the Australian Modification (ICD-10-AM 9th edition) for AP data.

Characteristics that may identify those in need of PC: Sociodemographic characteristics input into the model included in the analyses included age at death, sex, ethnicity, socioeconomic status, language preference, rurality and residence in an aged care home and diagnosis of death.

Comments: Useful in that shows the estimated vs actual need of palliative care in the region during the study period.

Table 6 provides a useful comparison of population needs estimates from similar studies to this one with publication dates ranging from 2016 to 2020

Jeba et al. (2021) Projecting palliative and end-of-life care needs in Central Lancashire up to 2040: an integrated palliative care and public health approach. *Public Health*, 195, pp.145-151.

Available from: <https://pubmed.ncbi.nlm.nih.gov/34116382/>

Model(s) tested: Gomez-Batiste et al. (2012), Murtagh et al. (2014), Etkind et al. (2017)

Summary: This population-based needs assessment involved secondary analysis of routinely available regional mortality and population data for Central Lancashire. Palliative care need was estimated using three recognised methods. Estimates were combined with routinely available population and mortality projections and observed trends in palliative care need to provide projections up to 2040.

Palliative care need in 2017 in Chorley & South Ribble and Greater Preston is estimated to be between 75% (1292) and 97% (1670), and 74.9% (1337) and 95.7% (1710) of all deaths, respectively. By 2040, the annual need is projected to increase compared with 2017 figures, by 24.2-55.9% (314-729 more deaths) in Chorley & South Ribble and by 13.4-41.4% (180-554 more deaths) in Greater Preston.

This needs assessment was used as the basis for a refreshed Local Palliative and End of Life Care strategy and used to articulate enhancement of 7-day specialist palliative care services across all settings.

Data collection: Data for 2012 to 2017 was obtained provided by Lancashire County Council Business Intelligence Team. Data from the Office for National Statistics was also collected

Characteristics that may identify those in need of PC: Age and cause of death

Comments: This is a more localised test of the models we identified. Authors noted the changes to ICD-10 coding system in 2022

Calvache et al. (2020) How many people need palliative care for cancer and non-cancer diseases in a middle-income country? Analysis of mortality data. *Colombian Journal of Anesthesiology*, 48(4).

Available from: <http://www.scielo.org.co/pdf/rca/v48n4/2256-2087-rca-48-04-e201.pdf>

Model(s) tested: Murtagh et al. (2014)

Summary: This cross-sectional study aimed to provide an estimate of the need for palliative care services in Colombia and compare these with the PC services currently available. Age and sex specific numbers of deaths and mortality rates for defined chronic illnesses between 2012-2016 were used to estimate the prevalence of palliative care need. The numbers of deaths requiring palliative care increased from 107,065 in 2012 to 128,670 in 2016 (61.2% of total deaths).

Data collection

The analyses are based on public and anonymized data from death certificates provided by National Administrative Department of Statistics of Colombia (DANE). Authors classified eight categories of conditions requiring palliative care (Malignant neoplasm, health and cerebrovascular disease, renal disease, liver disease, respiratory disease, neurodegenerative disease, Alzheimer's, dementia and senility, HIV/AIDS).

Characteristics that may identify those in need of PC:

Age, sex and underlying cause of death, geographical region.

Comments: This may not be generalisable as it's from Colombia. Figure 3A may be interesting, in that it contrasts the estimates of need for palliative care with the formal offer of services across different regions.

Morin et al. (2017) Estimating the need for palliative care at the population level: A cross-national study in 12 countries. *Palliative Medicine*. 31(6):526-536.

Available from: doi:[10.1177/0269216316671280](https://doi.org/10.1177/0269216316671280)

Model(s) tested: Rosenwax et al. (2005), French National Observatory on End of Life Care, Murtagh et al. (2014)

Summary: This cross-sectional study using death certificate data aimed to estimate the proportion of decedents potentially in need of palliative care across 12 EU and non-EU states. Three population-based estimation methods were tested. They each utilised different definitions of conditions indicating a need for palliative care. The French National Observatory and Murtagh methods of estimation used ICD-10 codes to categorise conditions, but Rosenwax included 10 specific diseases.

The proportion of individuals who died from diseases that indicate palliative care needs at the end of life ranged from 38% to 74%. The authors found important cross-country variation: the population potentially in need of palliative care was lower in Mexico (24%–58%) than in the United States (41%–76%) and varied from 31%–83% in Hungary to 42%–79% in Spain. Irrespective of the estimation methods, female sex and higher age were independently associated with the likelihood of being in need of palliative care near the end of life. Home and nursing home were the two places of deaths with the highest prevalence of palliative care needs.

Data collection:

Datasets used in the modelling was not provided in the paper.

Characteristics that may identify those in need of PC:

Characteristics used to determine the likelihood of being in need of palliative care included gender, age, marital status, and place of death.

Comments: Authors note it is important to acknowledge that while the study focused on the potential need for palliative care of patients at the end of life, they cannot tell for what period they would need this type of care.

Rosenwax et al. (2016) A retrospective population based cohort study of access to specialist palliative care in the last year of life: who is still missing out a decade on?. *BMC Palliat Care* **15**, 46.

Available from: <https://doi.org/10.1186/s12904-016-0119-2>

Model(s) tested: Rosenwax et al. (2005)

Summary: Retrospective cohort study that aimed to document changes in PC service delivery relative to the number of patients who could benefit from such services. Using data on last year of life of persons with an underlying cause of death in 2009–10 from cancer, heart failure, renal failure, liver failure, chronic obstructive pulmonary disease, Alzheimer's disease, motor neurone disease, Parkinson's

disease, Huntington's disease and/or HIV/AIDS (disease conditions considered as being amenable to receiving palliative care). The proportion of decedents receiving specialist palliative care was compared to a 2000–02 cohort.

The cohort included 12,817 deaths: 7166 (56 %) from cancer, 527 (4 %) from both cancer and non-cancer conditions and 5124 (40 %) from non-cancer conditions. Overall, 46.3 % of decedents received community and/or hospital-based specialist palliative care; a 3.5 % (95 % CI 2.3–4.7) increase on specialist palliative care access reported ten years earlier. The majority (69 %; $n = 4928$) of decedents with cancer accessed palliative care during the last year of life. Only 14 % ($n = 729$) of decedents with non-cancer conditions accessed specialist palliative care, however, this represented a 6.1 % (95 % CI 4.9–7.3) increase on the specialist palliative care access reported for the same decedent group ten years earlier. Compared to decedents with heart failure, increased odds of palliative care access was observed for decedents with cancer (OR 10.5; 95 % CI 9.1–12.2), renal failure (OR 1.5; 95 % CI 1.3–1.9), liver failure (OR 2.3; 95 % CI 1.7–3.3) or motor neurone disease (OR 4.5; 95 % CI 3.1–6.6).

Of the 46 % of the cohort who did access specialist palliative care, the median number of days under specialist palliative care was 25 days (IQR 8–75 days), and the temporal distribution of specialist palliative care access days in the last year life was skewed towards the weeks leading up to death. Over 60 % of total days of hospital-based palliative care occurred in the four weeks before death, but this varied greatly by the principal cause of death condition. Community-based palliative care tended to be accessed earlier in the last year of life.

Living in major cities, being female, having a partner and living in a private residence was associated with increased odds of access to specialist palliative care. Subgroup analysis restricted to non-cancer decedents identified those living in a care facility compared to a private residence (OR 0.4; 95% CI: 0.3–0.4; $p < 0.0010$) was the only social and demographic variable associated with reduced access to specialist palliative care.

Data Collection: A de-identified and linked extraction of death records, hospital morbidity records and community-based care records of persons who died in Western Australia (WA) from 1st January 2009 to 31st December 2010 was obtained from the Data Linkage Branch at the WA Department of Health.

Characteristics that may identify those in need of PC:

Social and demographic variables used for analyses included marital status at time of death, accessibility to services (geocoding of decedents address used, based on ARIA+ which considers road distance measurements to nearest service centre and population size), Index of Relative Social Disadvantage (geocoding) and residence at time of death. Logistic regression was used to examine these factors with access of palliative care. In the model accounting for all sociodemographic variables and the underlying cause of death condition living in areas of lower socioeconomic status was no longer associated with reduced access to specialist palliative care and the association of age at death was not as marked (when compared to not accounting for cause of death). **Decedents who were**

living in major cities, were female, had a partner and were living in a private residence at time of death still had increased odds of access to specialist palliative care after adjusting for the cause of death condition.

Comments: Little information was available on the severity of the disease condition assigned as being amenable to palliative care or whether the death was truly expected or not. Thus, it may not have always been clinically appropriate for the decedent to be referred to palliative care. Secondly, authors did not have data to estimate how much of normal care provided by residential aged care facilities could be classified as being palliative in nature, and thus, may be underestimating the level of palliative care being delivered in these facilities. And lastly, authors acknowledge they are also likely to be underestimating the access to specialist palliative care in rural areas because they relied on community based palliative care data from a single provider that is focused in urban areas. Measurement of improvements in access for patients living in rural and remote areas will require additional data to be conclusive. They also acknowledge that life limiting conditions that may benefit palliative care are likely to change over time, for example, HIV/AIDS. These temporal changes need to be considered when interpreting findings.

Scholten et al. (2016) The size of the population potentially in need of palliative care in Germany - an estimation based on death registration data. *BMC Palliative Care*, 15:29. DOI 10.1186/s12904-016-0099-2

Available from: <https://link.springer.com/article/10.1186/s12904-016-0099-2>

Model(s) tested: Rosenwax et al. (2005) and Murtagh et al. (2014)

Summary: This study aimed to estimate the size of the German population that may benefit from palliative care using German death registration data from 2013. To give further insight into age-related differences regarding the demand for PC, authors performed an additional analysis accounting for the factor "age". They estimated the demand for palliative care within the different age groups with the Murtagh method and the maximal estimate (Rosenwax method).

According to the method Rosenwax defined, between 40.7 % (minimal estimate) and 96.1 % (maximal estimate) of death cases could benefit from palliative care. The estimation, based on Murtagh's refined method, results in 78.0 % of death cases potentially being eligible for palliative care. The percentage of potential palliative care candidates is conditioned by age. Based on the Murtagh Method, in the age category between 30 and 39 years, a potential demand for palliative care can be found for 40.4 % percent of all deaths occurring in this age category, with this number increasing to 80.3 % in the age bracket of 80 years and over. The Rosenwax method concluded similar need, but on a higher level. The increase of potential palliative care needs with older age is caused by a change of

the cause of death from more external causes of death, like accidents, to more cases of death caused by diseases, potentially creating a need for palliative care (e.g. cancer and vascular diseases).

Data collection:

Number and causes of deaths were collected from The Federal Bureau of Statistics who hold a complete inventory count of all deaths in Germany. They also utilised the German Mortality Statistics from 2013. Authors reported as it was not possible to match mortality statistics with hospital admission data, this restricted the analyses they could undertake. It was also necessary to make some adaptations to convert the estimation methods to German data, particularly the defined codes to ICD-10-WHO year 2013 codes. This was necessary, as the ICD-Codes between countries and years can differ.

Characteristics that may identify those in need of PC:

Age, cause of death

Comments: Availability of data meant analyses was limited to age only. This study is based on a single year of data.

Kane et al. (2015) The need for palliative care in Ireland: a population-based estimate of palliative care using routine mortality data, inclusive of nonmalignant conditions. *Journal of pain and symptom management*, 49(4), pp.726-733.

Available from: <https://doi.org/10.1016/j.jpainsymman.2014.09.011>

Model(s) tested: Murtagh et al. (2014) (minimal estimate only)

Summary: This study used routine mortality data (2007-2011) inclusive of non-malignant conditions to estimate the potential population with generalist and/or specialist palliative care needs in Ireland.

During the period 2007–2011, there were 141,807 deaths. Eighty percent were from conditions recognized as having associated palliative care needs, with 41,253 (30%) deaths from cancer and 71,226 (50%) deaths from noncancer conditions. The majority of deaths, 81% (91,914), were among those ≥65 years. There was a 13.9% (901) increase in deaths of those ≥85 years. Deaths from dementia increased by 51.3%, with an increase in deaths from neurodegenerative disease (42.8%) and cancer (9.5%).

This study seems to emphasise the necessity for routinely collected data at a patient, service, and population level to inform policy makers of the need for palliative care service delivery and use, which was lacking at the time.

Data collection:

Routine mortality data (2007-2011) from the Irish Central Statistics Office (CSO) to identify deaths from palliative care-relevant conditions. As there is no linkage of hospital data with mortality data in Ireland, this limited the data authors could collect.

Characteristics that may identify those in need of PC:

Age and cause of death

Comments: Because of data limitations, it was only possible to apply the minimal estimate method described by Murtagh et al. (2014)

Tabl 3: Astudiaethau sylfaenol yn edrych ar nodweddion y rhai sydd angen gofal lliniarol

Quinn, K. L., et al. (2021). "Comparison of Palliative Care Delivery in the Last Year of Life Between Adults With Terminal Noncancer Illness or Cancer." JAMA network open **4**(3): e210677.

Available from: <https://pubmed.ncbi.nlm.nih.gov/33662135/>

Summary: This cohort study utilised the linked health administrative data of 145 709 adults who died of cancer or terminal noncancer illness and received palliative care in their last year of life in Ontario, Canada. Palliative care was initiated earlier (>90 days before death) in patients with cancer (32010 [28.9%]) than in those with organ failure (3349 [15.9%]; absolute difference, 13.0%) or dementia (2148 [15.3%]; absolute difference, 13.6%). A lower proportion of patients with cancer had palliative care initiated in the home (16088 [14.5%]) compared with patients with chronic organ failure (6904 [32.8%]; absolute difference, -18.3%) or dementia (3922 [27.9%]; absolute difference, -13.4%). Patients with cancer received palliative care across multiple care settings (92 107 [83.3%]) more often than patients with chronic organ failure (12061 [57.3%]; absolute difference, 26.0%) or dementia (7553

[53.8%]; absolute difference, 29.5%). Palliative care was more often delivered to patients with cancer (80615 [72.9%]) using a consultative or specialist instead of a generalist model compared with patients with chronic organ failure (9114 [43.3%]; absolute difference, 29.6%) or dementia (5634 [40.1%]; absolute difference, 32.8%). Patients with cancer (42 718 [38.6%]) received shared palliative care more often from general practitioners and physicians with subspecialty training, compared with patients with chronic organ failure (3599 [17.1%]; absolute difference, 21.5%) or dementia (1989 [14.2%]; absolute difference, 24.4%).

Characteristics of those in need of PC: disease group, age, sex, socioeconomic status, rural location of residence, comorbidities and chronic conditions, hospital fragility score

Limitations: The study did not measure delivery of palliative care by health care practitioners other than physicians, which may include nurse practitioners or social workers. The study intentionally used information on a patient's death certificate to define the cohort to maximize specificity because of the concern that other approaches may introduce too much heterogeneity and other sources of bias

Alqahtani, F., et al. (2019). "Utilization of palliative care in patients hospitalized with heart failure: A contemporary national perspective." *Clinical cardiology* **42**(1): 136-142.

Available from: <https://onlinelibrary.wiley.com/doi/10.1002/clc.23119>

Summary: This population study used administrative data from the USA to assess national trends in palliative care utilisation in patients admitted to hospital with acute heart failure. The study found that of 939,680 patients admitted to hospitals with acute heart failure, 1.2% received palliative care during their hospitalisation. Patients who received PC were older (79 ± 12 vs 69 ± 16 years, $P < 0.001$), Caucasians (73.4% vs 51.8%, $P < 0.001$), and had a higher prevalence of coronary artery disease (45.6% vs 39.3%, $P < 0.001$), chronic renal disease (79.3% vs 42.8%, $P < 0.001$), pulmonary hypertension (28.3% vs 15.1%, $P < 0.001$), and other key comorbidities compared with those who did not receive PC. In a multivariate logistical regression analysis, the strongest predictors of referring to PC were: older age (OR 14.17, 95% CI 9.53-21.09 for age > 85 , and OR 6.18, 95% CI 4.18-9.15 for age 65-85 [reference age 18-40]), cardiogenic shock (OR 6.17, 95% CI 5.15-7.40), chronic renal failure (OR 4.19, 95% CI 3.75-4.68), and mechanical ventilation (OR 2.49, 95% CI 1.85-3.35). Racial minorities were less likely to receive PC than Caucasian patients, respectively: (OR 0.56, 95% CI 0.49-0.64) for African-American vs Caucasian, and (OR 0.53, 95% CI 0.43-0.65) for Hispanic vs Caucasian. Geographic differences in PC utilization were also observed with higher utilization in hospitals located in the West (OR 1.59, 95% CI 1.38-1.83).

Characteristics of those in need of PC: Age, ethnicity, disease group, co-morbidities, geography.

Limitations: Authors appear to have an NIS administrative database used for billing purposes to gather data, which is limited by erroneous coding.

Szekendi, M. K., et al. (2016). "The Prevalence of Inpatients at 33 U.S. Hospitals Appropriate for and Receiving Referral to Palliative Care." *Journal of palliative medicine* **19**(4): 360-372.

Available from: <https://www.liebertpub.com/doi/10.1089/jpm.2015.0236>

Summary: A multisite cross-sectional, retrospective point prevalence analysis to determine the size and characteristics of the population of inpatients at 33 U.S. Authors also conducted a qualitative assessment of barriers and facilitators to referral, focusing on organizational characteristics that might influence palliative care referral practices. A total of 2,618 in-patients met the study criteria for inclusion. Among those appropriate for referral, 29.8% received a referral and 31.6% received palliative care services, although in some cases these services (such as physical therapy or psychological counselling) were provided without a referral to or consultation with the palliative care team. Patients with two or more conditions were most likely to receive a palliative care referral (40.5% versus 35.8% for patients with poor-prognosis cancer only, 26.1% for patients with advanced COPD only, and 21.6% for patients with advanced CHF only). The proportion of patients receiving referrals was fairly consistent across age groups, with the exception of patients over the age of 84 year, who were referred more often. Referral practices varied by U.S. geographic region. We found that 36.4% of patients appropriate for referral received a referral at hospitals located in the Northeast, compared with 31.9% at hospitals in the West, 25.8% in the South, and 25.3% in the Midwest ($p < 0.05$ comparing Northeast and South and comparing Northeast and Midwest).

Of patients appropriate for referral, almost 80% had either Medicare (57.3%) or commercial health care (22.2%) coverage.

Characteristics of those in need of PC: Age, disease group, multi-morbidities

Limitations: Authors note that their estimated prevalence is a conservative figure and may underestimate the unmet need to palliative care. In addition, findings reflect bias related to differences among hospitals in charting and coding practices. Palliative care service offerings (e.g., inpatient beds, ambulatory services) differed among participating hospitals.

Beernaert et al. (2013) Referral to palliative care in COPD and other chronic diseases: a population-based study. *Respiratory Medicine*. **107**;11 1731-1739

Available from: <https://doi.org/10.1016/j.rmed.2013.06.003>

Summary: This population-based study utilised data from Belgium GP practices to describe how patients with COPD, heart failure, dementia and cancer differ in frequency and timing of referral to palliative care services. Of 2405 registered deaths respectively 5%, 4% and 28% were identified as from COPD, heart failure or cancer and 14% were diagnosed with severe dementia. Patients with COPD (20%) were less likely than those with heart failure (34%), severe dementia (37%) or cancer (60%) to be referred to palliative care services ($p < 0.001$). The median days between referral and death was respectively 10, 12, 14 and 20.

Female cancer patients were more likely to be referred to palliative care services than their male counterparts (OR 1.46, 95% CI 1.05 to 2.05). Patients with heart failure (OR 3.33, 95% CI 1.07 to 10.43) and dementia (OR 1.75, 95% CI 1.02 to 2.99) were more likely to be referred when they lived in a nursing home than when they lived at home, while the opposite was found for cancer patients. No significant associations were found in the multivariate analyses for patients with COPD (Table 3). There were no significant associations between socio-demographic characteristics and the timing of onset of palliative care services for the four disease groups (not in table).

Characteristics of those in need of PC: diagnosis, main residence last year of life, age, sex,

Limitations: With a low number of patients with COPD and heart failure referred statistical power for sub analyses for those patients (e.g. timing of referral) was low.

Currow et al. (2008) Populations who die without specialist palliative care: does lower uptake equate with unmet need? Palliative Medicine. 22(1):43-50. doi:10.1177/0269216307085182

Available from: <https://journals.sagepub.com/doi/pdf/10.1177/0269216307085182>

Summary: The aim of this study was to understand, at a population level, the perceived unmet needs in four key subpopulations who have been reported to have less access to SPCS: 1) those with non-cancer diagnoses (analysis of cancer versus noncancer); 2) those of substantially older age (analysis of individuals 75 years and older, versus younger); 3) those with lower household incomes (analysis of less than AU\$60 000, versus more); and 4) those of non-English speaking backgrounds (analysis by country of birth, English versus non-English speaking). The null hypothesis was that there would be no differences observed in unmet needs in people who did and did not access specialized palliative care services.

As part of a broader state-wide randomized face-to-face population health survey over six years (18 224 interviews, 71% response), questions were asked of people bereaved in the previous five years when someone close to them died an 'expected' death (39% of respondents). Questions included respondent demographics, the diagnosis of the deceased and, for one year, whether SPCS was of benefit (if used) or needed (if not used). Differential uptake rates were calculated for diagnosis, income, country of birth and age and 2 × 2 tables reflecting the accuracy of match of service with caregiver needs were generated for each group (accuracy = true positives + true negatives/total).

Uptake of SPCS was significantly lower in people with a non-cancer diagnosis (40% versus 62%; $P < 0.0001$), lower income (56% versus 61%; $P = 0.0006$) and people born where English was not the first language (52% versus 58%; $P = 0.0096$). The only subgroup where the accuracy of matching between palliative care service uptake and identified needs was lower than the overall average (83%) was where cancer was not the life-limiting illness (69%; cancer 86%).

Characteristics of those in need of PC: Disease diagnosis of decedent, age, first language, household income of respondent

Limitations: Utilising proxy data to gather information about those accessing PC does not identify those with a caregiver.

Currow et al. (2004) Specialist palliative care needs of whole populations: a feasibility study using a novel approach. Palliat Med. 18(3):239-47. doi: 10.1191/0269216304pm873oa. PMID: 15198137

Available from: <https://pubmed.ncbi.nlm.nih.gov/15198137/>

Summary: This cross-sectional study sought to determine the feasibility of a novel whole-population method for determining specialist palliative care services (SPCS) uptake and need. The hypothesis was that the whole community could provide population-based reports about deceased individuals to help in service evaluation and planning. An annual survey of 4400 people, which has been conducted since 1991 - the South Australian Health Omnibus survey included four questions on palliative care (year 2000 survey). The study provides an initial step in the process of evaluating a novel way of defining the denominator for a whole-of population approach to people with a life-limiting illness who may need access to SPCS.

Of the respondents who indicated that a person 'close to them' had died, 507 (47%) indicated that the person was followed by a SPCS (Table 1). Excluding 'don't know' as a response, 55.2% indicated that a SPCS was involved. People who died of cancer more frequently accessed palliative care than those with nonmalignant life-limiting illnesses (cancer 61% versus noncancer 36%, $P < 0.001$, Table 2). If a proxy relationship between the respondent's and the deceased's characteristics is assumed, rates of access to SPCS were similar regardless of country of birth, educational level, or residential region (metropolitan 55% versus regional rural 57%, $P = 0.659$, Table 2). Respondents whose income was more than AU\$60 000 per year were more likely to report the use of palliative care services ($> \$60\,000$ 62% versus $< \$60\,000$ 52%, $P = 0.010$, Table 2) and less likely to report that family and friends took the caring role as a reason for not using a SPCS ($> \$60\,000$ 55% versus $< \$60\,000$ 67%, P for trend across all answers to question 4 = 0.050, table 3).

Where there was an identified death, 404 respondents (38%) definitely indicated that a palliative service had not been used by the PLLI (Table 1). Reasons cited included: family and friends provided the care (137, 34%), the service was not wanted (86, 21%), and other (107, 27%). In the 'other' category, frequently identified themes were that the person was an inpatient at the time of death, that the time between diagnosis and death was short, or that the person died 'suddenly' or 'unexpectedly.'

People with a non-English speaking background more commonly indicated that SPCS were not wanted because family and friends looked after the deceased person (non-English speaking background 76% versus English-speaking background 63%, P for trend across all answers to question 4 = 0.114, Table 3). People who died of cancer and did not access SPCS were more commonly cared for by family and friends than people with a noncancer illness (cancer 43% versus noncancer 31%, P for trend across all answers to question 4 = 0.034, Table 3)

If successful, such a tool can help service planning for all PLLI and their carers, compare outcomes (including bereavement follow-up) for those who do and do not use SPCS, and track trends over time.

Characteristics of those in need of PC (Statistically significant in bold): cancer or non-cancer diagnosis of decedent,
Country of birth, educational level, residential region, annual household income, native language of respondent (all non-significant)

Limitations: This was a proxy survey design and questions asked were limited in the information they gathered. Fifty-six of the original 4400 people contact declined to contribute to the survey because of language barriers. Any interpretation of the data around people for whom English was not their first language is limited.



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Iechyd Cyhoeddus
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Public Health
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Y Gwasanaeth Tystiolaeth
Adroddiad Cwmpasu

Cyfeiriadau

1. Crowther et al. (2013) Palliative care for dementia – time to think again? Q J Med; 106:491–494 doi:10.1093/qjmed/hct078. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3665910/pdf/hct078.pdf>
2. Davies et al. (2019) Socioeconomic position and use of healthcare in the last year of life: a systematic review and meta-analysis. PLOS Medicine. 16 (4). <https://doi.org/10.1371/journal.pmed.1002782>

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www.nationalarchives.gov.uk/doc/open-government-licence/version/3/ ar yr amod y
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