

General Data Management Health Check

Systematically perform basic clean-up functions

| Activity | |
|--|---------------|
| Deactivate patients | Performed Y/N |
| Best Practice – mark a patient inactive | |
| Medical Director – deactivate a patient | |
| Genie – edit patient | |
| Mark patient as deceased | Performed Y/N |
| Best Practice – mark patient as deceased | |
| Medical Director – flagging patients as deceased | |
| Genie – edit patient | |
| Check for missing dates of birth and gender | Performed Y/N |
| Best Practice – searching the database | |
| Medical Director – editing a patient's details | |
| Genie – custom reports | |
| Merging duplicate files | Performed Y/N |
| Best Practice – merge patient records | |
| Medical Director – merging patient records | |
| Genie – edit patient | |

Adapted from Cancer Screening Toolkit – Cancer Institute NSW 2019



Diagnoses excluded from screening

The tools used to generate patient lists from your software excludes:

- patients with particular diagnoses in their record
- patients who have 'opted out' for screening (manually excluded) for personal or clinical reasons – CAT4 does not exclude these but some software systems may).

This function helps to limit the possibility of sending reminders to patients inappropriately or unnecessarily. Some patients may opt back in overtime depending on their personal or clinical circumstances

What diagnoses are excluded from screening by software?

Colorectal exclusions

| | Cancer of the bowel | Polyps |
|---|--|--|
| CAT4 Codes used by PEN to mark patients as 'ineligible' | <ul style="list-style-type: none"> • Anal carcinoma • Cancer of the anus • Carcinoma of the anus • Squamous cell carcinoma of anus • Adenocarcinoma of the colon • Bowel cancer • Cancer of the colon • Carcinoma of the colon • Colon carcinoma • Colonic cancer • Colonic carcinoma • Cancer of the rectum • Carcinoma of the rectum • Rectal adenocarcinoma • Rectal cancer • Rectal carcinoma • Genetic tendency to hereditary nonpolyposis colorectal cancer • Hereditary nonpolyposis colorectal carcinoma • Lynch syndrome • Carcinosarcoma of the colon • Colon carcinosarcoma • Signet ring cell carcinoma of bowel • Signet ring cell carcinoma of rectum | <ul style="list-style-type: none"> • Familial adenomatous polyposis • Familial polyposis coli • Gardner's syndrome • Hereditary polyposis coli • Multiple colonic polyps • Polyposis coli • Adenomatous colonic polyp • Adenomatous colonic polyps • Colonic polyp • Colonic polyps • Polyp, colonic • Polyps, colonic • Polyp, rectal • Polyps, rectal • Rectal polyp • Rectal polyps • Polyposis coli • Rectal polyp removal • Removal of rectal polyp • Rectal polyp, removal • Rectal polypectomy • Removal of rectal polyp • Colonic polyp, removal • Colonic polypectomy • Removal of colonic polyp |
| Medical Director and Genie | N/A | |



Mammogram exclusions

| | | |
|---|---|--|
| <p>CAT4</p> <p>Codes used by PEN to mark patients as 'ineligible'</p> | <ul style="list-style-type: none"> • Adenocarcinoma – Breast • Breast cancer • Breast carcinoma • Breast carcinosarcoma • Breast removal • Carcinoma – Breast • Carcinosarcoma of the breast • Mastectomy - partial and node biopsy | <ul style="list-style-type: none"> • Radical mastectomy • Radical mastectomy • Signet ring cell carcinoma of breast • Simple mastectomy • Surgery – Mastectomy • Surgery - Radical mastectomy • Surgery - Radical mastectomy • Surgery - Simple mastectomy |
| Medical Director and Genie | N/A | |

Pap Smear / Cervical screening exclusions

| | | |
|---|---|--|
| <p>CAT4</p> <p>Codes used by PEN to mark patients as 'ineligible'</p> | <ul style="list-style-type: none"> • Hysterectomy • Hysterectomy - Abdominal • Hysterectomy - Laparoscopic • Hysterectomy - ovary(ies) spared • Hysterectomy - Vaginal • Hysterectomy - Vaginal with vaginal repair • Hysterectomy & BSO – Abdominal | <ul style="list-style-type: none"> • Surgery - Uterus - Hysterectomy • Uterus - removal of • Vaginal Hysterectomy |
| Medical Director | Cervical screening result searches | |
| Genie | Genie report | |

Extracting lists of excluded patients

Bowel screening

| | |
|------------------|--|
| CAT4 | Cancer screening searches will produce a pie chart. Click on segment for 'ineligible' and export to excel using standard process |
| Medical Director | N/A |
| Genie | N/A |

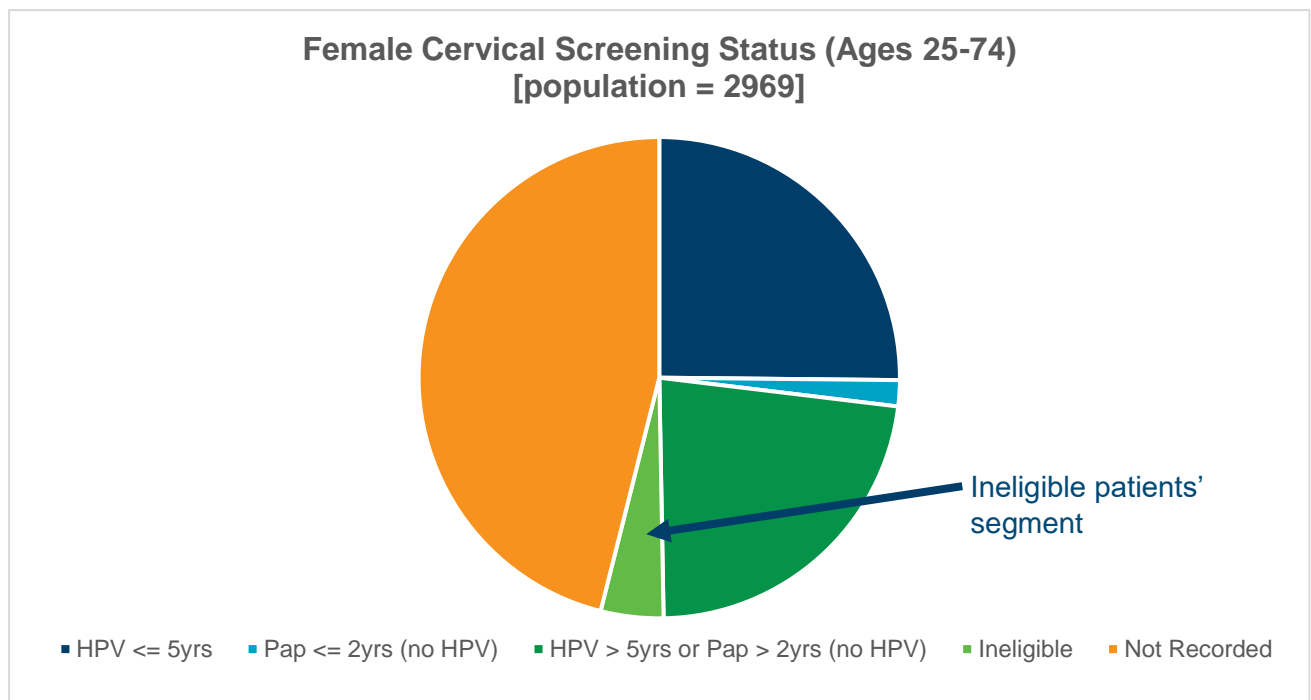
Breast screening

| | |
|------------------|--|
| CAT4 | Cancer screening searches will produce a pie chart. Click on segment for 'ineligible' and export to excel using standard process |
| Medical Director | N/A |
| Genie | N/A |

Cervical screening

| | |
|------------------|--|
| CAT4 | Cancer screening searches will produce a pie chart. Click on segment for 'ineligible' and export to excel using standard process |
| Medical Director | Excluding patients from cervical screening searches |
| Genie | Genie report |

CAT4 example: pie chart 'ineligible' patients



Checking lists for potential eligible patients

Once you have the ineligible patient list it is important to have a GP or nurse check it for patients that may now be able to return to screening.

Inform any patients returning to the screening program of why they have been included back into the program/s prior to placing them back into your reminder system.

Not overlooking transgender and intersex patients

ALL patients need access to screening programs, regardless of physical sex characteristics or gender identity.

Care needs to be taken to ensure that intersex, trans, and gender diverse patients are captured and not inadvertently overlooked in data and reminder systems.

Understanding the meaning of intersex, transgender, and gender diversity

Intersex

“Intersex is a term that relates to a broad range of congenital physical traits or variations that lie between ideals of male and female. Intersex people are born with physical, hormonal, or genetic features that are neither wholly female nor wholly male, or a combination of female and male.

Many forms of intersex exist; it is a spectrum or umbrella term, rather than a single category. At least 30 or 40 different variations are known to science. Intersex differences may be apparent at birth. Some common intersex variations are diagnosed prenatally. Some intersex traits become apparent at puberty, or when trying to conceive, or through random chance.”¹

According to Intersex Human Rights Australia, intersex clients need the following:

- clear messages that a service welcomes intersex people, and an awareness that intersex status is about variations of biology, not gender identity or sexual orientation
- to know that confidentiality will be respected
- services that understand intersex health and wellbeing concerns.

Printable version of - [making your service Intersex friendly](#)

Transgender and gender diverse

Transgender and gender diverse are described as individuals who identify to a different gender than that assigned to them at birth (ACON).

Gender diverse people may identify outside of the male and female binary. Identities may include non-binary, gender-fluid, gender non-conforming, trans masculine, and trans feminine, etc.

Transgender is independent of sexuality, meaning they will also have a sexual orientation which could be heterosexual, lesbian, gay, bisexual, etc.

1. ¹ Hunter New England and Central Coast Primary Health Network: Cancer Screening Handbook, 2018. Available at <https://www.hnecphn.com.au/media/14971/hnecphn-cancer-screening-handbook-to2019-to2.pdf> (accessed Dec 2019).



Eligibility of transgender and intersex patients for breast and cervical screening

ALL patients aged 25 to 74 years, who have a cervix and have been sexually active, should have a cervical screen. This includes people who were assigned the gender of female at birth but no longer identify as such, even if they have had the HPV vaccination.

Gender categories – data audit tools and practice software

CAT4 gender categories:

- male
- female
- other (gender other/diverse)
- not stated/inadequately described.

Breast and cervical reports will include patients listed as:

- female
- other (includes patients listed as 'intersex' in practice software)
- not stated/inadequately described.

| Category | Patients included | Action | Completed |
|----------------|---|---|-----------|
| Female | Patients not eligible for screening (patients who do not have a cervix). | Manually capture to ensure they do not receive a reminder. | |
| Other/Intersex | Patients who identify as male or non-binary but are eligible for screening. | Ensure patients who are assigned this category are eligible prior to adding to reminder list. | |
| Male | Patients identifying as male who are eligible for screening (patients who have a cervix). | Manually capture these patients to ensure access to screening. This group will not be included in lists generated for breast or cervical screening. | |



Register for transgender and intersex patients

Maintaining a register of patients who identify as transgender, gender diverse, or intersex could be utilised to cross-check lists.

This type of register can help to ensure that only patients who are clinically eligible to participate in specific screening programs receive reminder notifications.

Consideration of changing patient information forms

Patient information forms give your patients the opportunity to tell you:

- how they identify themselves
- if they are trans, gender diverse, or intersex
- how you should address them.

Questions for consideration (taken from ACON's CheckOut clinic registration form)

1. What is your current gender identity?

- Female
- Male
- Non-binary
- Different identity (open field here)

2. What sex were you assigned at birth?

- Female
- Male

3. Were you born with a variation of sex characteristics (this is sometimes called 'intersex')?

- Yes
- No
- Prefer not to say

4. What are your pronouns? (You can select more than one)

- She / Her / Hers
- He / Him / His
- They / Them / Theirs
- Other (open field here)

Screening comparisons

| Patient group | Bowel cancer screening participation | BreastScreen Australia screening participation | Cervical cancer screening participation |
|--|--------------------------------------|--|--|
| Aboriginal or Torres Strait Islander peoples | 21% | 39.1% | When compared with non-Aboriginal or Torres Strait island communities: Incidence: > double Mortality: x4 higher |
| Non-Aboriginal or Torres Strait Islander | 43.3% | 54.3% | |
| Non-English speaking or people who speak a language other than English at home | 24.7% – 34.1% | 49.8% | “People from culturally and linguistically diverse backgrounds are less likely to participate in cervical screening.” ¹ |
| English spoken at home | 42.8% – 46.4% | | |
| People with a disability | 36% | Data not available | “People with disabilities are less likely than the general population to attend cervical screening.” ² |
| People without a disability | 43.2% | | |
| People identifying as LGBTIQ+ | Data not available | Data not available. Unique clustering of risk factors for breast cancer are experienced in this group. ³ | Less likely than the general population to attend cervical screening. ⁴ |
| People living: Very remotely | 27.5% | 44.1% | 46.3% |
| Major cities | 40.4% | 53.3% | 56.4% |
| Outer regional areas | | 56.9% | 56.6% |
| Men | 39% | Limited differentiation between socioeconomic groups. | 50.4% |
| Women | 43% | | |
| Lowest Socioeconomic status group | 39% | Limited differentiation between socioeconomic groups. | 62.1% |
| Highest Socioeconomic status group | 43% | | |
| Other | | People recalled for further assessment and found not to have breast cancer are less likely have subsequent screenings. | People who have experienced sexual assault or have undergone genital cutting are less likely to participate in screening. ⁵ |

Unless otherwise specified, information accessed from Australian Institute of Health and Welfare reports.



Northern Queensland Primary Health Network acknowledges the Traditional Custodians of the lands and seas on which we live and work, and pay our respects to Elders past and present.

References

1. Department of Health. Women from CALD backgrounds, including women who have experienced female genital cutting. Available at <http://www.cancerscreening.gov.au/internet/screening/publishing.nsf/Content/cervical-toolkit-engaging-under-and-never-toc~section%E2%80%93engaging-withgroups~cald> (accessed 6 June 2019)
2. Australian Institute of Health and Welfare. Women with disabilities. Available at <http://www.cancerscreening.gov.au/internet/screening/publishing.nsf/Content/cervical-toolkit-engaging-under-and-never-toc~section%E2%80%93engaging-withgroups~disabilities> (accessed 6 June 2019)
3. ACON. LGBTQ Risk Factors for Breast Cancer. Available at <https://www.ourunitedfront.org.au/lgbtq-risk-factors> (accessed 4 June 2019)
4. ACON. Welcome to the Inner Circle. Available at <https://www.theinnercircle.org.au/> (accessed 6 June 2019)
5. Department of Health. Toolkit for engaging under-screened and never-screened women in the National Cervical Screening Program: Under-screened and never-screened women. Available at <http://www.cancerscreening.gov.au/internet/screening/publishing.nsf/Content/cervical-toolkit-engaging-under-and-nevertoc~section%E2%80%93under-never-screened> (accessed 6 June 2019)