Seychelles Oncology Unit Patient Survey

Technical Handbook

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Preface

This handbook is a guide on the design, development, training, and implementation of the **Seychelles Oncology Unit Patient Survey**. This handbook was first put together for the first iteration of the survey in 2025.

This is a pre-release version (**v0.0.0.9000**) released on **14 April 2025**.

Part I

Design

1 Survey design

2 Questionnaire design and development

The key approach to questionnaire design and development for this project was to build on existing tried and tested oncology patient satisfaction and/or experience survey instruments utilised in other countries and in various contexts to ensure content validity (see Section 2.1 for a description of these questionnaires). Questions from these existing instruments were either extracted verbatim or were modified to align with the local context. Localisations included adjustments to terminology to match what is used locally and the addition of response options relevant to the Seychelles local setting and specific cultural context of the population. The questionnaire design was further guided by the six domains of healthcare quality (see Note 1) put forth by the Institute of Medicine or IOM[1].

> **Note 1: IOM six domains of healthcare quality**
>
> **Safe**: Avoiding harm to patients from the care that is intended to help them.
> **Effective**: Providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and misuse, respectively).
> **Patient-centered**: Providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.
> **Timely**: Reducing waits and sometimes harmful delays for both those who receive and those who give care.
> **Efficient**: Avoiding waste, including waste of equipment, supplies, ideas, and energy.
> **Equitable**: Providing care that does not vary in quality because of personal characteristics such as geographic location and socioeconomic status.

2.1 Reference questionnaires

Following are the reference questionnaires used by the study team to develop the Seychelles Oncology Unit Patient Survey.

2.1.1 Le Baromètre cancer

The *Le Baromètre cancer* is a nationwide survey carried out in France every five years. Now on its fourth edition which collected data collected in 2021 from nearly 5000 individuals aged 15 to 85, the survey offers insight into how the French population perceives and responds to cancer which are then used in the for public health monitoring and research.

The survey is run by Santé publique France in collaboration with the Institut National du Cancer. Given the survey's every five years frequency, it is able to provide data that can be analysed to track trends over time in how people perceive cancer, their awareness of prevention methods, and how they engage with screening programs.

For the purpose of the survey questionnaire development for this study, the Baromètre cancer questionnaire for 2015 was used[2].

2.1.2 Cancer Awareness Measure Plus

The *Cancer Awareness Measure Plus (CAM+)* is a recurring survey designed to collect nationally representative data on public attitudes, awareness, and behaviours in the United Kingdom regarding key areas such as early diagnosis, screening, and cancer prevention. The findings from CAM+ are utilised by Cancer Research UK to guide strategic decision-making, operational planning, communication efforts, and the development of behavioural interventions, as well as to inform evidence-based policy development.

The original *Cancer Awareness Measure (CAM)* survey was developed and validated between 2007 and 2008 through a collaboration between Cancer Research UK, University College London, King's College London, and the University of Oxford, in response to the absence of a validated tool for assessing public awareness of cancer. In addition to the general CAM, a series of cancer-specific CAMs were also developed. These instruments were initially designed to be administered via face-to-face or telephone interviews.

Since 2008, Cancer Research UK has routinely collected CAM and CAM+ data. While the frequency of data collection has varied over time, biannual data collection was established in 2020, with a transition to annual data collection planned for the future.

Beginning in 2014, the survey has been continuously updated, modified, and expanded to reflect emerging evidence and changes in the external environment. These enhanced iterations are referred to as the *Cancer Awareness Measure Plus (CAM+)*, highlighting the inclusion of additional questions and substantial revisions to the original instrument. In 2019, the survey was further adapted to facilitate online data collection.

For the purpose of the survey questionnaire development for this study, the 2011 version of the toolkit for the original CAM developed in 2008[3] was used along with the 2019 version of the CAM+[4].

2.1.3 Consumer Assessment of Healthcare Providers and Systems

The *Consumer Assessment of Healthcare Providers and Systems (CAHPS®)* is a long-term initiative by the Agency for Healthcare Research and Quality (AHRQ) aimed at improving understanding of patient experiences in healthcare. It supports research to develop valid and practical tools for assessing and reporting patient experiences, and for using these insights to enhance care quality. Over its more than 25-year history, CAHPS has produced standardized surveys widely used by healthcare providers and policymakers to evaluate and improve patient care across various settings.

Launched in 1995 to address inconsistent and limited data on patient perspectives, CAHPS initially focused on health plans. It has since expanded to cover a broader range of healthcare services. Now in its sixth phase (CAHPS VI, as of 2022), the program continues to evolve while maintaining its voluntary, research-focused nature.

For the purpose of the survey questionnaire development for this study, the CAHPS® Cancer Care Survey for drug therapy version was used[5].

2.2 The Seychelles Oncology Unit Patient Survey questionnaire

The current development process has produced a 59-item survey instrument composed of 6 sections (see Note 2).

> **Note 2: Survey instrument sections**
>
> **Section 1**: Demographics (10 questions)
> **Section 2**: Patient journey to diagnosis and referral to Oncology Unit (9 questions)
> **Section 3**: Communication and interacting with the Oncology Team (29 questions)
> **Section 4**: Scheduling and access (6 questions)
> **Section 5**: Comfort and evironment (3 questions)
> **Section 6**: Overall experience (2 questions)

2.2.1 Demographics

The **Demographics** section collects patient charactertistics information on

- age;
- gender;
- location of residence;
- disability status;
- languages spoken;
- marital status;
- level of education;
- employment status;
- type of occupation/job; and,
- living arrangements.

Demographic information allows us to perform stratified analysis of patients' reported experience of cancer care potentially detecting inequities/disparities.

2.2.2 Patient journey to diagnosis and referral

The **Patient journey to diagnosis and referral to Oncology Unit** section elicits patients' experience before reaching the Oncology Unit with a focus on assessing their knowledge, attitudes, and practices/behaviours on help-seeking. In addition, this section draws information on how the general health service/system performs in getting the patient to a confirmed diagnosis and eventual referral.

2.2.3 Communication and interaction

The **Communication and interacting with the Oncology Team** section draws out the patients' experience of and satisfaction with their communiations and interactions with the Oncology Team once they have been referred to the unit with the aim of assesing the patient-centredness of care once referred to the Oncology Unit.

2.2.4 Scheduling and access

The **Scheduling and access** section obtains the patients' experience of and satisfaction with the scheduling and access to the Oncology Unit both in terms of routine and urgent care. This assesses the timeliness and responsiveness of care once referred to the Oncology Unit.

2.2.5 Comfort and environment

The **Comfort and environment** section asks patients of their satisfaction with the overall level of comfort and the various aspects of the physical space and amenities available at the Oncology Unit.

2.2.6 Overall experience

The final seciton on **Overall experience** elicits the patients' satisfaction with the overall experience of the services at the Oncology Unit.

3 Data management plan

4 Data analysis plan

Part II

Training

5 Participant selection

6 Informed consent

7 Paper-based data collection

8 Electronic data collection

Part III

Deployment

9 Deploying the survey instrument

10 Data extraction, transformation, and loading pipeline

11 Data analysis workflow

References

1. Institute of Medicine (US) Committee on Quality of Health Care in America. *Crossing the Quality Chasm: A New Health System for the 21st Century*. (National Academies Press (US), Washington (DC), 2001).
2. *Baromètre Cancer 2015. Questionnaire*. (2018).
3. Cancer Research UK, University College London, Kings College London & University of Oxford. *Cancer Awareness Measure (CAM) Toolkit*. https://www.cancerresearchuk.org/sites/default/files/cam_2008_toolkit.pdf (2011).
4. The cancer awareness measure – public lifestyle UK survey (CAM PLUS) questionnaire. (2019).
5. *CAHPS Cancer Care Survey*. https://www.ahrq.gov/cahps/surveys-guidance/cancer/index.html (2020).

A Mobile device setup

Mobile devices such as mobile phones and tablets have become valuable tools in data collection. Various applications have been and are being developed specifically to harness the utility of mobile devices for collecting data. An understanding of how mobile devices work specifically those powered by Android operating system is therefore a requisite knowledge for anyone involved in a data collection campaign that utilises these devices for data collection. This tutorial gives a brief overview on how to get started with an Android device. We chose to focus on the use of tablet devices because we think that the smaller sized tablets (up to 7-inch) are a good mix of the mobility and handiness of a mobile phone and the wider screen size of a tablet which is good for fitting relatively dense question sets adequately. We also chose to focus on Samsung-branded because they are probably the most common brand of mobile devices available and we think most users have most likely had an experience using devices from this brand beforehand. We use the Samsung SM-T230 as the model device for instructional purposes.

A.1 Device layout

(a) Front

(b) Back

Figure A.1: Samsung SM-T230 device layout

Buttons

Power

- Press and hold to turn the device on or off.
- Press and hold for 8 seconds to reset the device if it has fatal errors or hangs-up, or freezes.
- Press to lock the device. The device goes into lock mode when the touch screen turns off.

Recent apps

- Tap to open the list of recent applications.

Home

- Press to return to the Home Screen.
- Press and hold to launch Google search.

Back

- Tap to return to the previous screen.

Volume

- Press to adjust the device volume.

A.2 Charging the battery

Before using the device for the first time or when the battery has been unused for extended periods, you must charge the battery.

Connect the USB cable to the USB power adaptor and then plug the end of the USB cable into the multipurpose jack.

- The device can be used while it is charging, but it may take longer to fully charge the battery.
- If the device receives an unstable power supply while charging, the touch screen may not function. If this happens, unplug the charger from the device.
- While charging, the device may heat up. This is normal and should not affect the device's lifespan or performance. If the battery gets hotter than usual, the charger may stop charging.

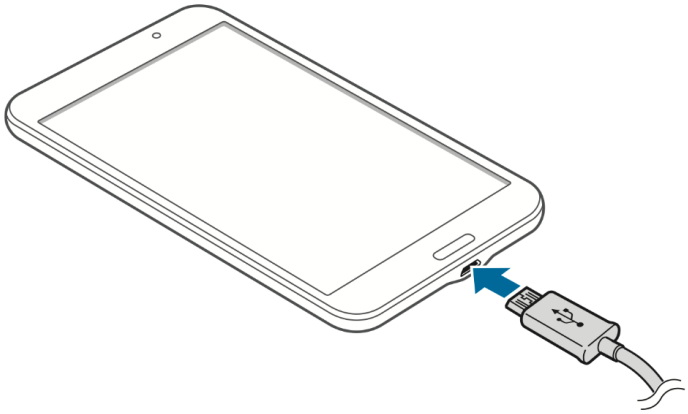


Figure A.2: Charging the device

After fully charging, disconnect the device from the charger.

Your device provides options that help you save the battery power. By customising these options and deactivating features in the background, you can use the device longer between charges:

- When you are not using the device, switch to sleep mode by pressing the Power button.
- Close unnecessary applications with the task manager.
- Deactivate the Bluetooth feature.
- Deactivate the WiFi feature.
- Deactivate auto-syncing of applications.
- Decrease the backlight time.
- Decrease the brightness of the display.

A.3 Turning the device on and off

When turning on the device for the first time, follow the on-screen instructions to setup your device.

Press and hold the Power button for a few seconds to turn on the device.

To turn off the device, press and hold the Power button, and then tap Power off.

A.4 Locking and unlocking the device

When not in use, lock the device to prevent unwanted operation. Pressing the Power button turns off the screen and puts the device into lock mode. The device automatically gets locked

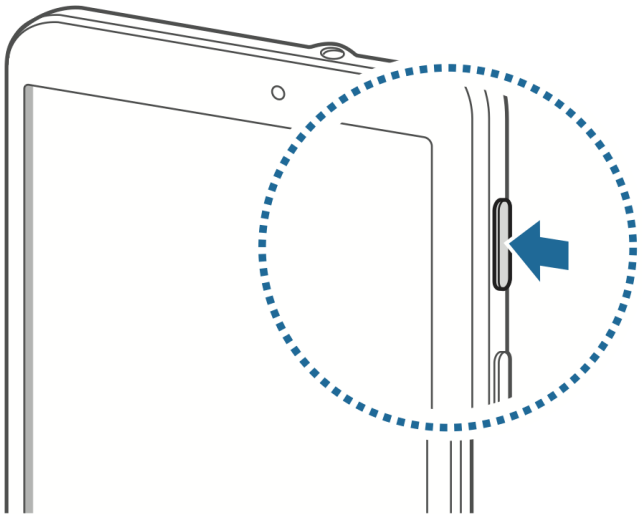


Figure A.3: Turning off the device

if it is not used for a specific period.

The steps to unlocking the device depends on the lock screen settings of the mobile device. By default, the **swipe** method will unlock the screen. This is done by pressing the Power button or Home button when the touch screen is turned off, tapping anywhere on the screen, and then swiping on the touch screen in any direction. See Section A.5.3.4 to learn more about the other lock screen methods.

A.5 Configuring devices for data collection

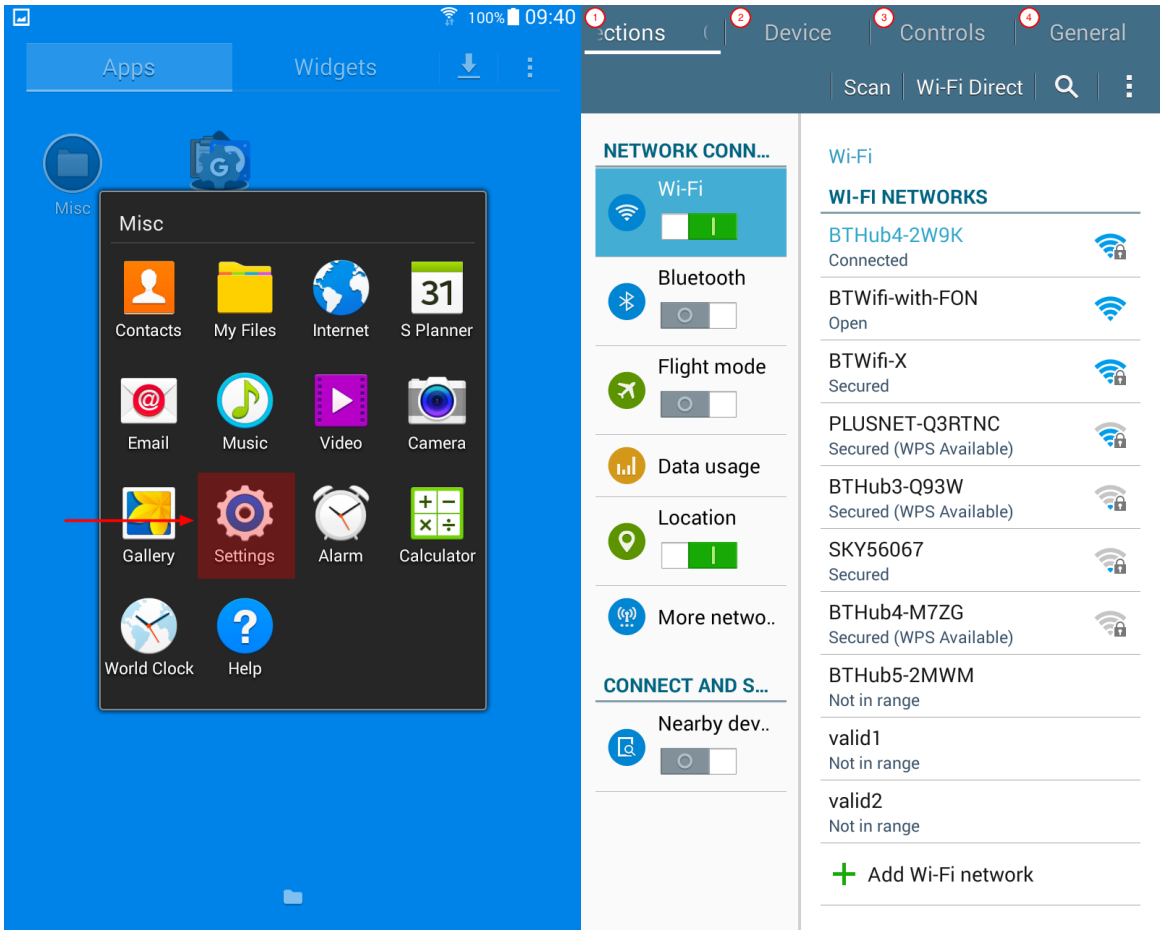
It is important to configure mobile devices such as mobile phones or tablets that are going to be used for data collection. From the point of view of a **survey lead** or **survey manager**, it will be important that the devices are configured in such a way that:

- Prevents inappropriate use by enumerators;
- Conserves the battery power of the device; and,
- Maximises its use for data collection.

A.5.1 Go to settings

On your tablet device, tap on the *Settings* app (Figure A.4a).

You will then see the following on your tablet screen (Figure A.4b). There are four (4) tabs on top of the screen named **Connections**; **Device**; **Controls**; and **General**. These are the four settings categories that can be configured as needed.



(a) Settings app (b) Settings menu

Figure A.4: Android device settings

A.5.2 Configure the Connections settings

Under the **Connections** tab (Figure A.5), the following settings should be configured:

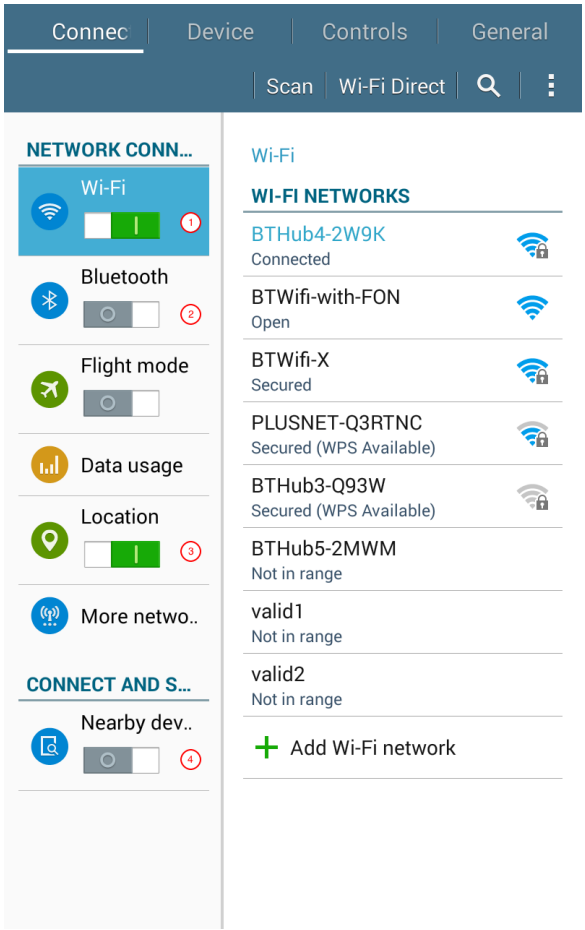


Figure A.5: Connections menu

- **Wi-Fi (1)** - this should be set to OFF during the data collection process. When ON, the device keeps on scanning for Wi-Fi networks that are available
- **Bluetooth (2)** - the Bluetooth should be set to OFF during the data collection process. When Bluetooth is ON, the device keeps on scanning for Bluetooth devices to connect to. This continuous scanning will drain the batter device very quickly.
- **Location (3)** - this should be set to ON during the data collection process if you will be collecting GPS coordinates.
- **Nearby devices (4)** - this should be set to OFF. This settings uses near-field communication (NFC) to communicate with other devices that are NFC-enabled. Just like Bluetooth, when turned ON, the device will keep on scanning to look for devices to connect to which will drain the battery device very quickly.

A.5.3 Configure the Device settings

Tap on the **Device** tab.

A.5.3.1 Sound and display settings

The first settings to configure will be the **Sound and Display** (Figure A.6).

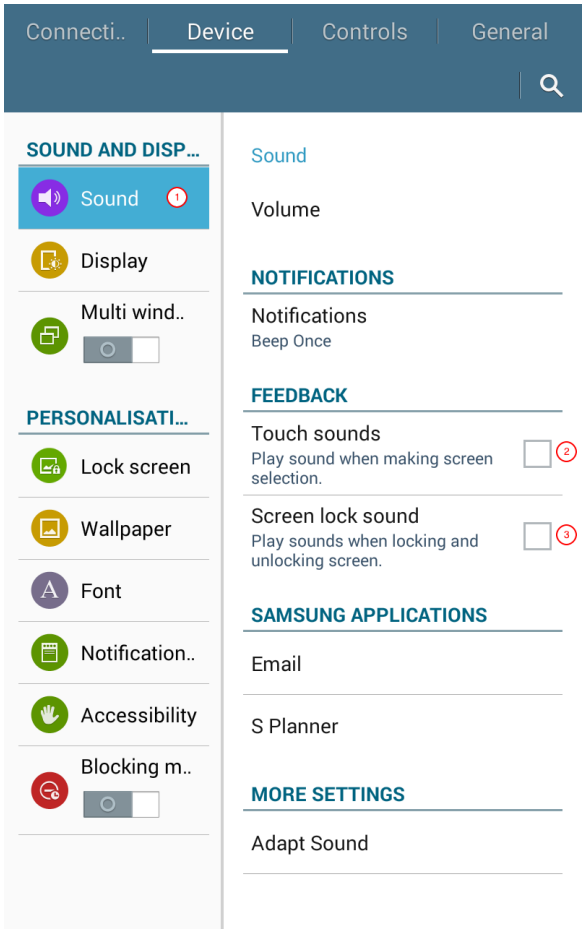


Figure A.6: Sound settings

For **Sound (1)**, the most relevant settings to configure will be whether you would want to get sound-based feedback when you interact with the device such as touching the screen and making selections **(2)** and when you lock or unlock the device **(3)**. These settings are checked by default as most users prefer some form of feedback when they tap on the screen or when they lock or unlock the screen. Uncheck this option if you prefer not to have these sounds on. These settings have very little effect on the device battery life and is more a matter of preference.

A.5.3.2 Display settings

Next, tap on **Display (1)** settings under the **Device** tab settings (Figure A.7).

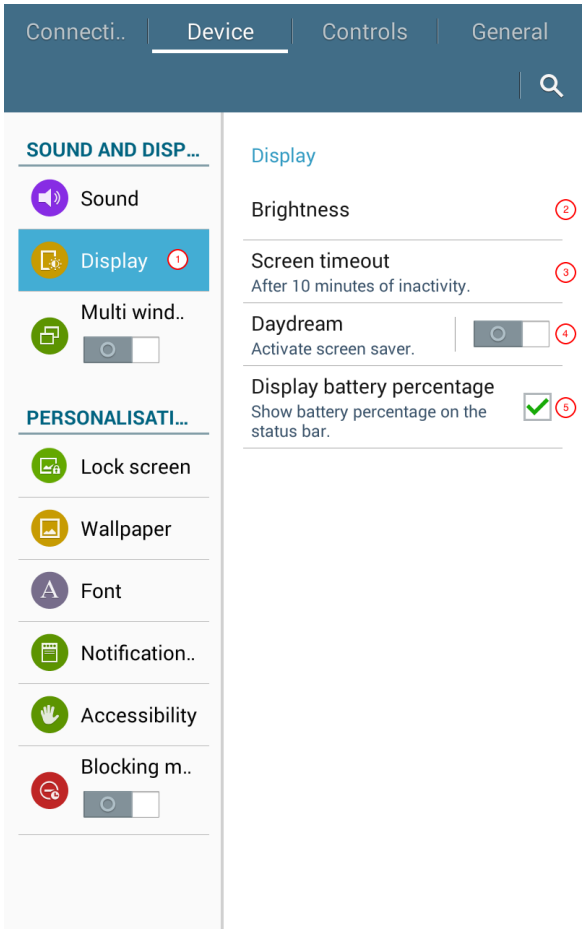


Figure A.7: Display settings

The following settings can be configured here:

- **Brigthness (2)** - this should be configured as needed but ideally should be set to no more than middle level brightness. Make sure that screen brigthness is not set to maximum at any point as this will drain the battery device very quickly.
- **Screen timeout (3)** - this setting determine how long the screen stays on when device is not in use. This should be set to about 10 minutes of inactivity. This is just about enough time for enumerators to ask questions and get a response and then record on the device without the screen going OFF and then the device going on lock.
- **Daydream (4)** - this is the screensaver for these devices. This should be turned OFF because when activated, a screen saver turns on when the device is inactive instead of the screen turning OFF and getting locked. This causes battery device drainage.

- **Display batter percentage (5)** - this should be checked. This will help enumerators to determine whether their devices have enough power or not.

A.5.3.3 Multi window settings

Next tap on **Multi window (1)** settings (Figure A.8). This should be unchecked **(2)**. For the purposes of data collection, there is no use for the multi window functionality.

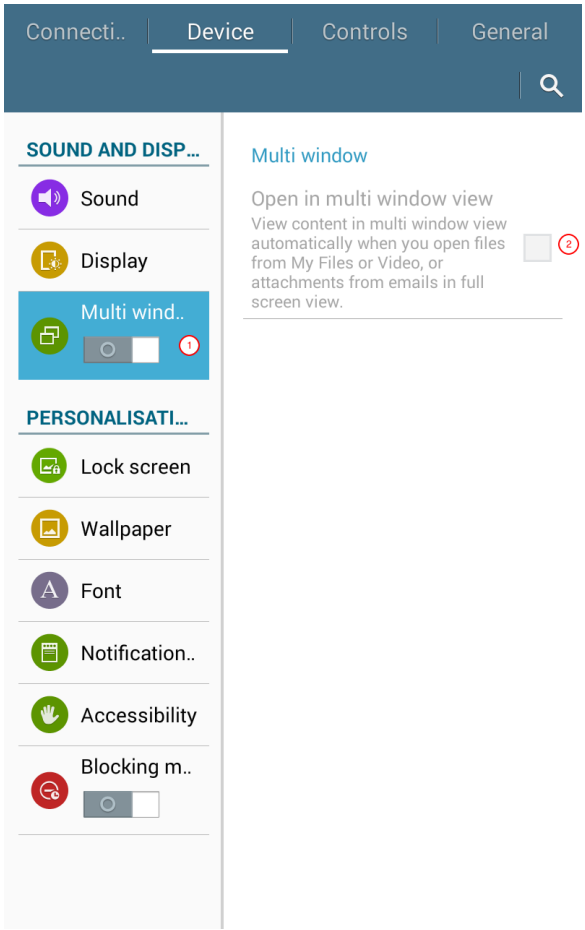


Figure A.8: Multi window settings

A.5.3.4 Lock screen settings

Next tap on the **Lock screen (1)** settings (Figure A.9). Under this setting, there are three main things we need to configure.

The **Owner information (2)** setting would be good to configure because this allows you to name the device you are setting up. This is especially important when you are managing

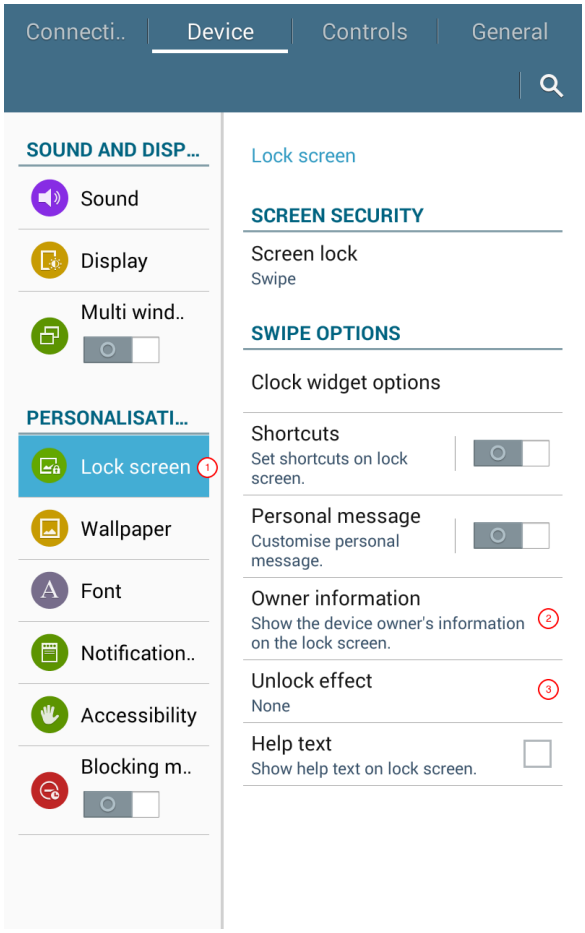


Figure A.9: Lock screen settings

multiple devices for data collection and you need to identify one device from the other so you know what device goes to which enumerator and other management task.

The **Unlock effect (3)** setting should also be configured to **None**. This setting ensures that unlocking of the device is quick and easy without unnecessary effects.

The **Screen Security** setting should be configured as this provides a layer of security on the mobile device that will enable only authorised users to access the contents of the mobile device and add/change settings of the mobile device. There are currently five options for screen security: **none**, **swipe (default)**, **pattern**, **PIN**, and **password**. It is recommended to set a screen lock method of either a pattern, PIN, or password. Figure A.10 shows an example of a screen lock pattern security for a mobile device.

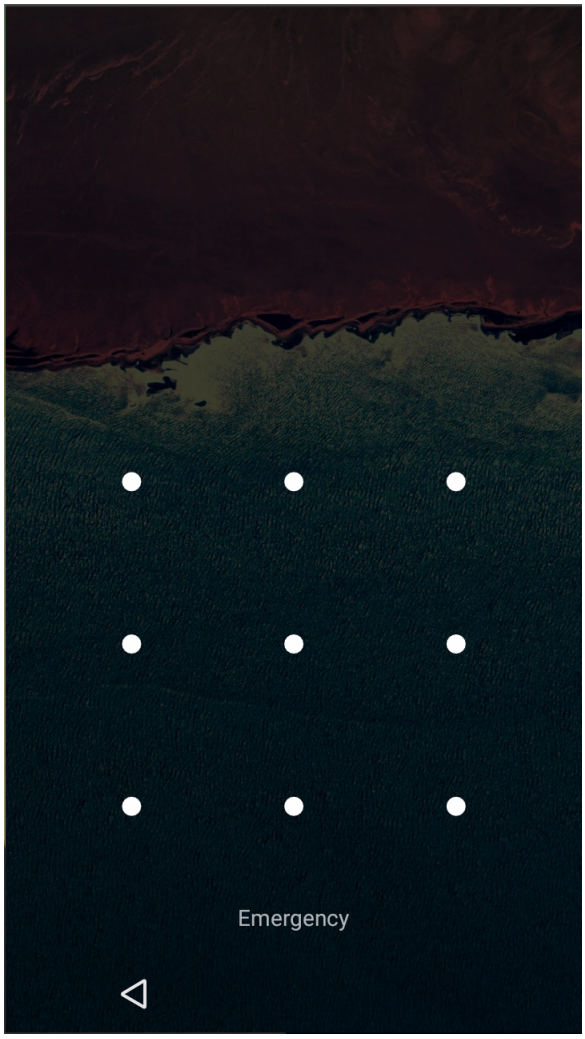


Figure A.10: Screen lock pattern example

A.5.3.5 Font settings

Now, tap on **Font** setting (Figure A.11).

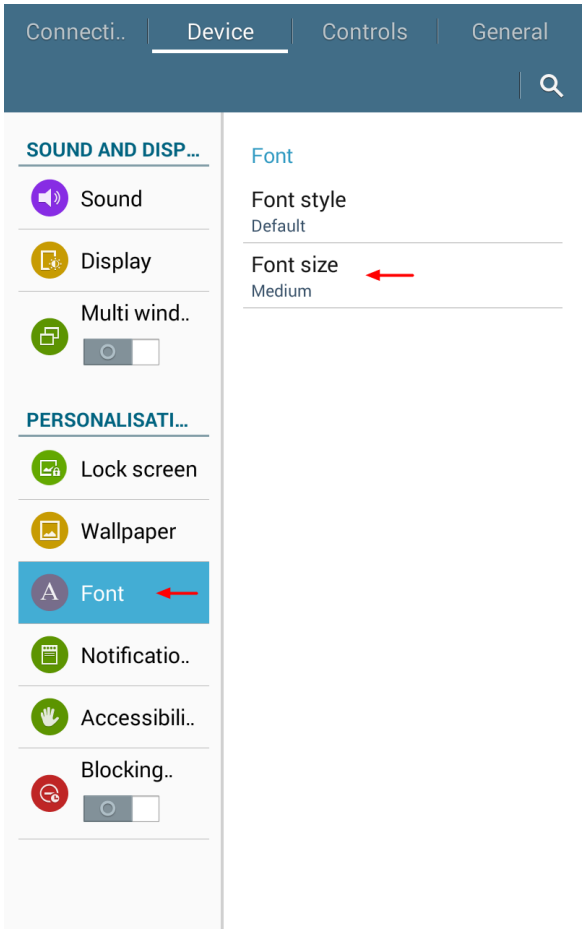


Figure A.11: Font settings

Here, there is one key setting to consider and that is the **Font size**. You should consider the best font size that would make the text of the device easier to read for enumerators. The device defaults to **Medium** which is generally a good font size to use. Change this font size if you think a bigger or smaller font would be necessary.

A.5.4 4. Configure the Controls settings

Now, tap on the **Controls** settings tab on top of the screen.

A.5.4.1 Language and input settings

The first setting to configure is the **Language and input (1)** settings (Figure A.12).

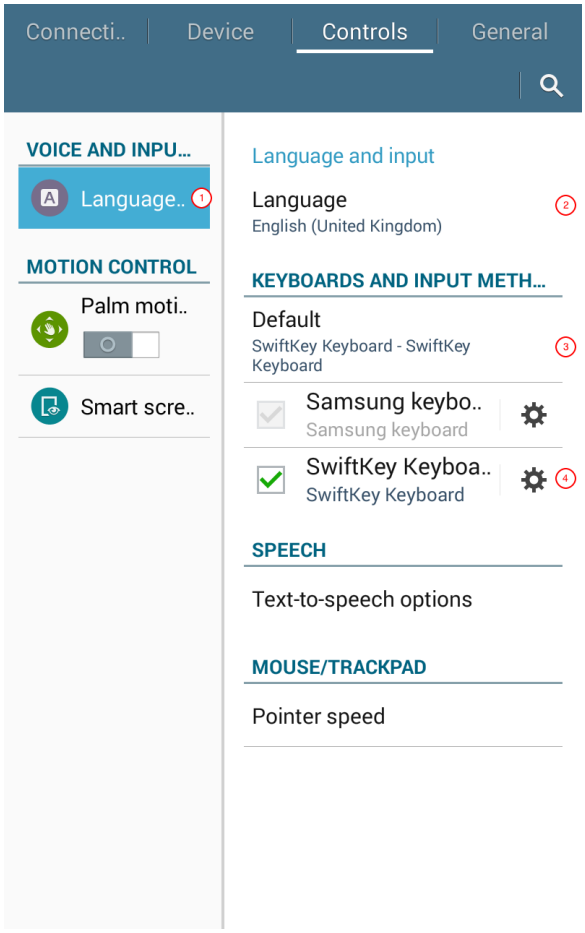


Figure A.12: Language and input settings

The language used in the device can be configured to the language that is most appropriate for the data collection. When the **Language (2)** setting is set to a particular language, the device uses that language throughout the device. In this example, the device is set to **English (United Kingdom)**.

The next setting is **Keyboards and input methods**. By default, Samsung devices uses the Samsung keyboard. However, there are various keyboard applications now available that provide much better keyboard input than the default Samsung keyboard. We recommend the use of **SwiftKey keyboard** as the layout of the keyboard is much better than the Samsung keyboard which allows for much accurate text entry.

To be able to enable SwiftKey, you first need to download and install the SwiftKey application from the Google Play Store or sideload it using an APK file. Once installed, the SwiftKey keyboard option now becomes available in the **Keyboards and input methods (4)** settings. This keyboard option can now be checked. Checking this keyboard option includes SwiftKey keyboard as a keyboard choice for the user. To make it default, tap on the **Default** setting of the **Keyboards and input methods**, and then select SwiftKey as the default keyboard **(3)**.

A.5.4.2 Palm motion settings

Now, set the **Palm motion (1)** setting (Figure A.13).

Turn off the setting for both **Capture screen (2)** and **Mute/Pause (3)** setting. This avoids enumerators unintentioally activating this gesture input which can confuse them on what to do next.

A.5.4.3 Smart screen settings

Now, set the **Smart Screen (1)** settings (Figure A.14).

You should uncheck the **Smart stay (1)** option. Whilst this setting is a clever functionality, this can drain the battery device much quicker because it utilises the front camera to determine whether the user is looking at the screen or not.

A.5.5 Configure the General settings

Next, tap on the **General** settings tab.

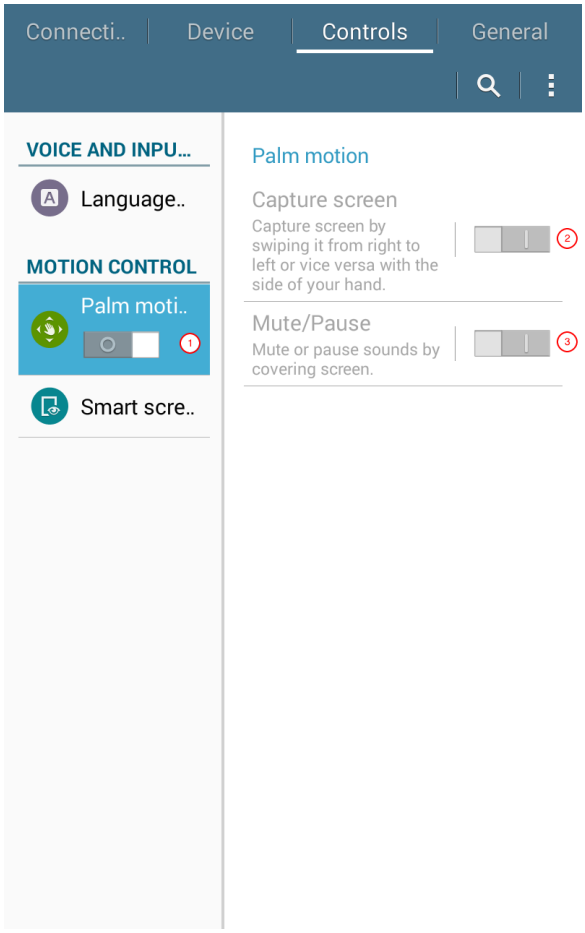


Figure A.13: Palm motion settings

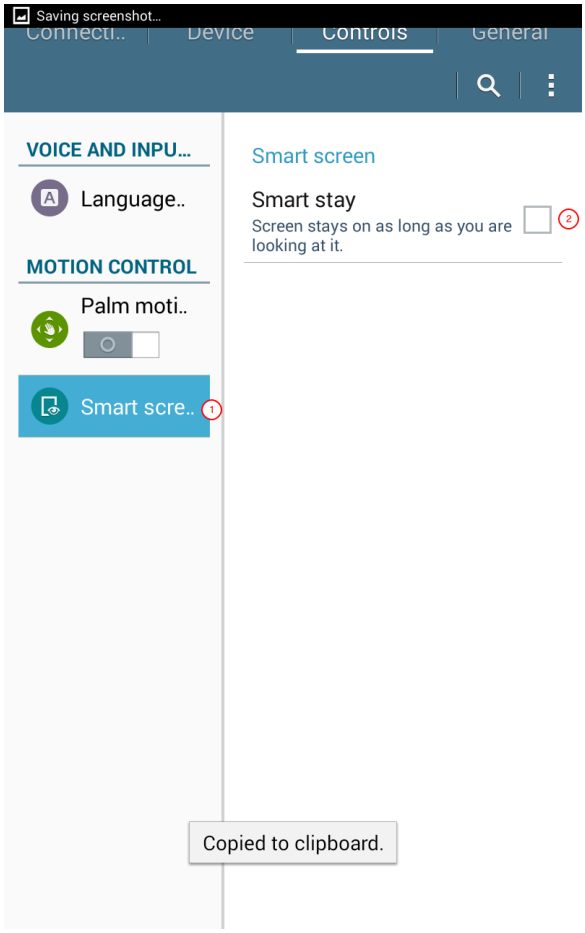


Figure A.14: Smart screen settings

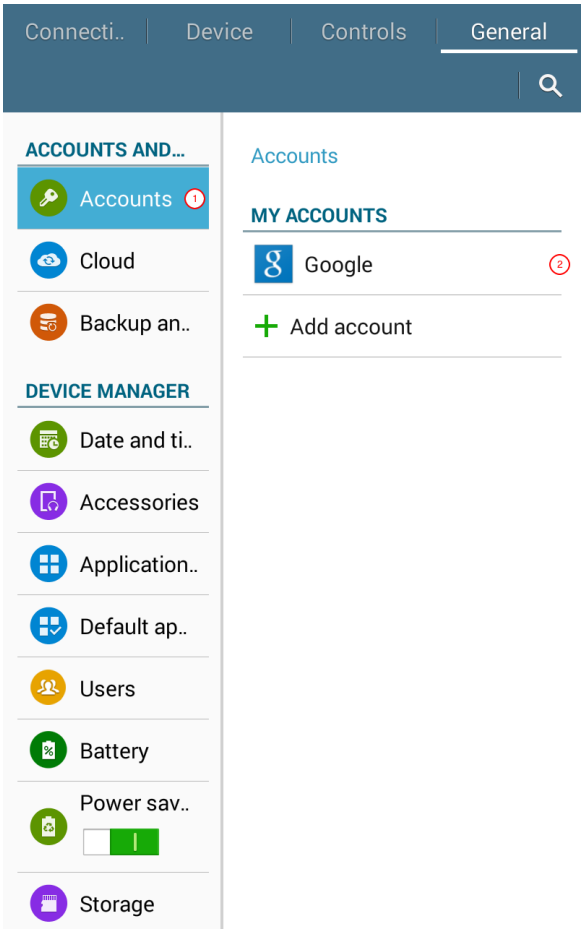


Figure A.15: Accounts settings

A.5.5.1 Accounts settings

The **Accounts (1)** setting is the first to configure (Figure A.15).

If you have already configured your device with a Google account, you should see under the **Accounts** section the Google icon **(2)**. If not, this is the time to add your Google account. Click on **Add account** and then follow the instructions after that.

Other accounts can be added here. However, for purposes of data collection, there is no for these other accounts unless your data collection campaigns requires any other accounts setup in your device.

A.5.5.2 Date and time settings

Now, we should set the **Date and time** settings (Figure A.16).

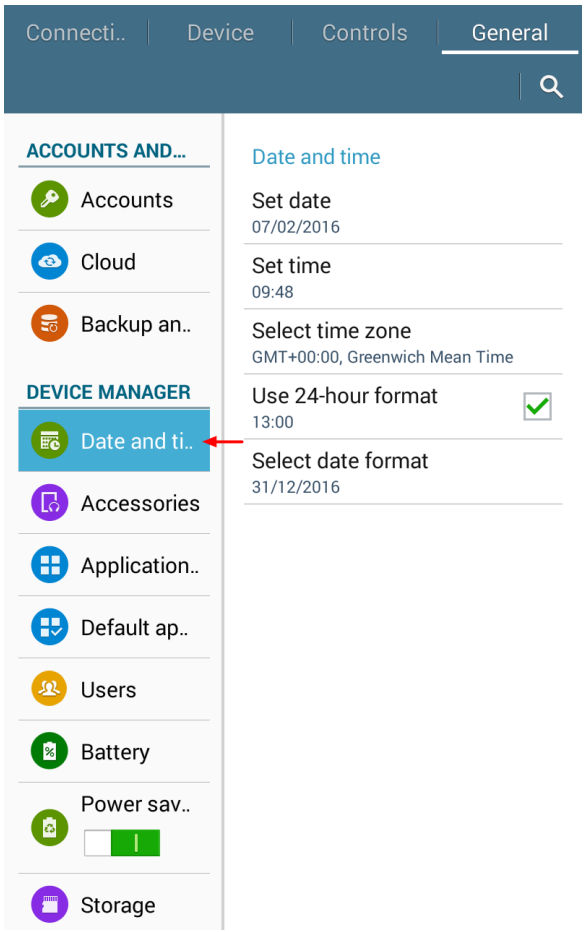


Figure A.16: Date and time settings

It would be important to set the **Date and time** settings of the device appropriately. This is relevant to data collection because some forms that collects dates uses the date and time

of the device to determine what the current date and time is. If these settings are not set correctly, then the recorded date and time in the forms will also be incorrect.

A.5.5.3 Application manager settings

Next, tap on the **Application manager** (Figure A.17).

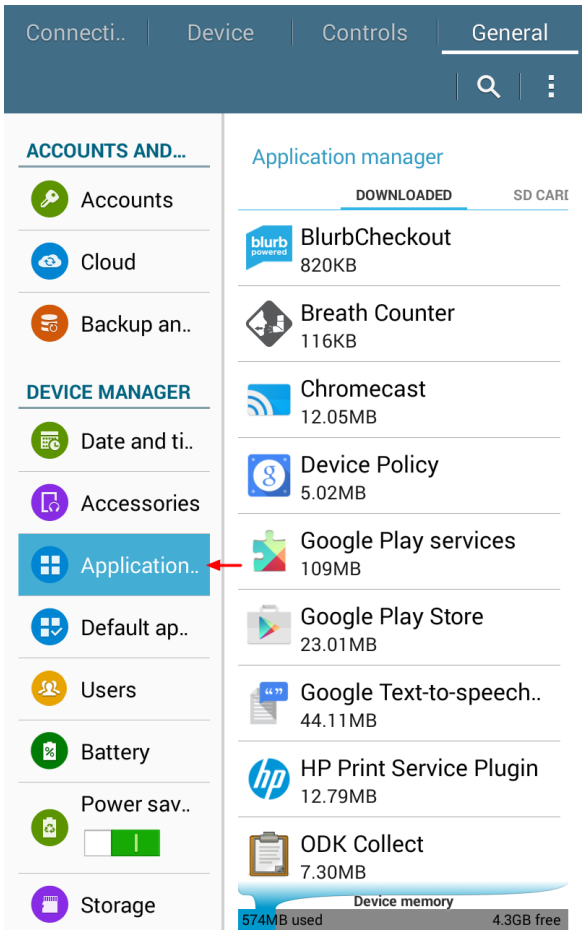


Figure A.17: Application manager settings

This setting allows you to disable or uninstall certain applications that is not really needed for your data collection. It is recommended that you disable or uninstall any applications installed on the device that will not be used by the enumerators for data collection. Doing so prevents unintended use of the device by the enumerators and ensures that the battery of the device is conserved and used only for data collection as much as possible.

It should be noted however that certain applications come pre-installed by the brand manufacturers. For some of these, they cannot be uninstalled or disabled as they have been hard set to stay on the device.

A.5.5.4 Power saving mode settings

Next, tap on **Power saving mode (1)** settings (Figure A.18).

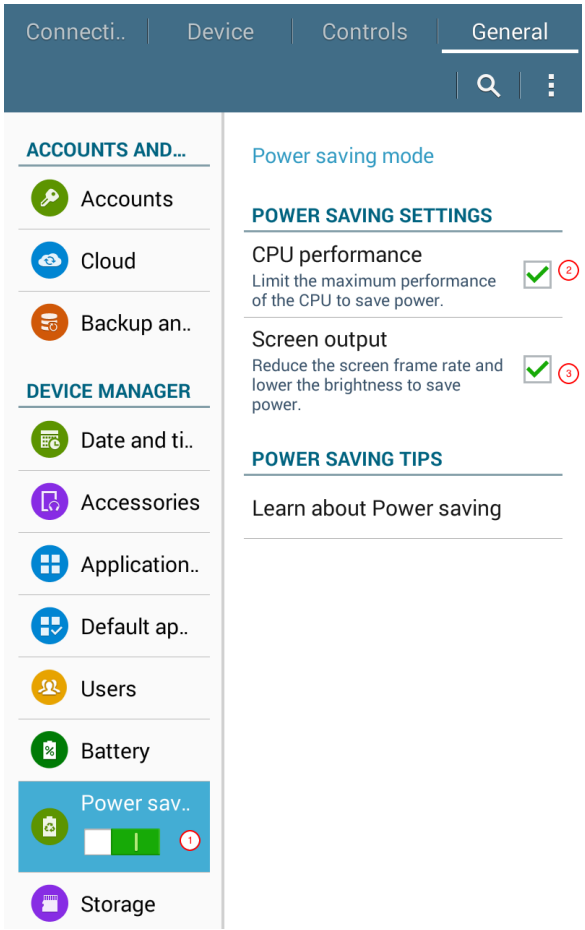


Figure A.18: Power saving mode settings

The **CPU Performance (2)** option can be checked. Data collection doesn't require great CPU performance at all and definitely will not require maximum performance at any point. This will increase battery life of the device.

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