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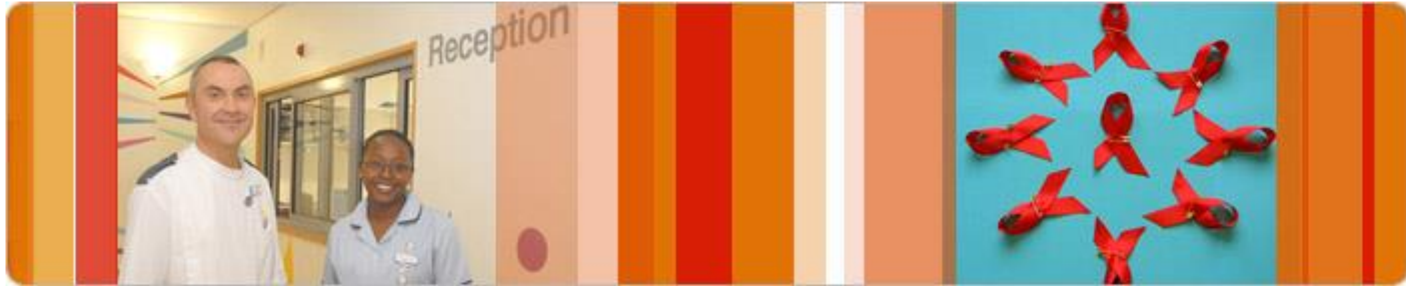

Disability in an inner city HIV rehab clinic

Will Chegwidden
Senior Occupational Therapist, Neurosciences & HIV, Royal London Hospital, Barts Health NHS Trust

13 June 2013 **International Forum on HIV and Rehabilitation Research**

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- UK's largest NHS Trust consisting six hospitals
- Turnover of £1.5billion
- Workforce of 15,000
- Catchment area of 2.5 million patients in East London
- Royal London is the newly built eighteen storey flagship
- Home to a major trauma centre and the helicopter emergency service

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Royal London Hospital Therapy Service

- Redesigned in 2011
- Integrated OT/PT teams
- Seven day working from 0800 – 1800
- reduced capacity
- State of the art facilities (five therapy gyms) but currently under-utilised

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HIV Services at the Royal London Hospital

Ward 13F

- 22 bed ward shared with respiratory
- Two four bed bays and fourteen ensuite rooms including ten negative pressure rooms

Grahame Hayton Unit

- Outpatient HIV and immunology clinic
- Still housed in an old building along with sexual health OP
- 2543 HIV attendees in 2012/13

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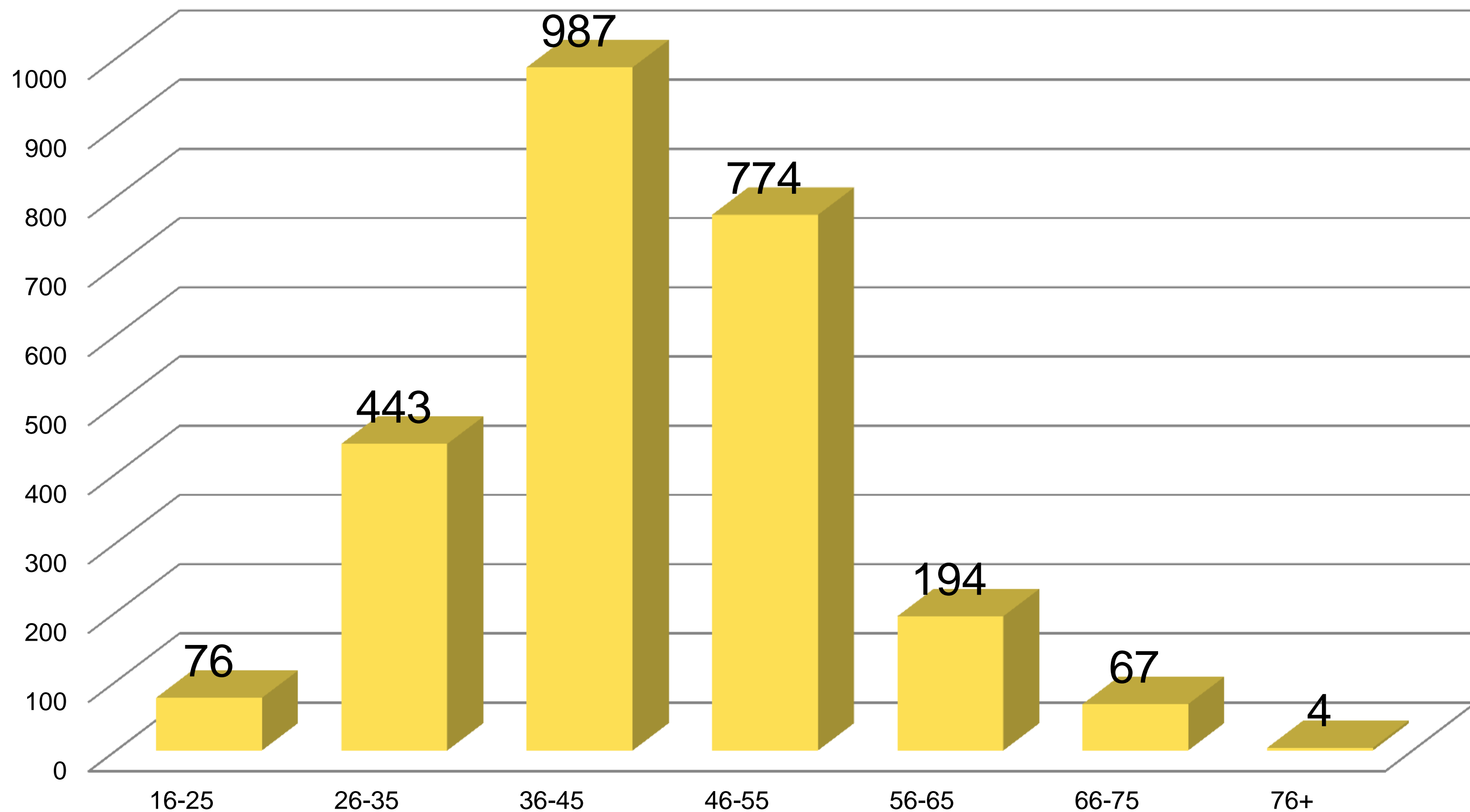
Grahame Hayton Unit – HIV outpatients



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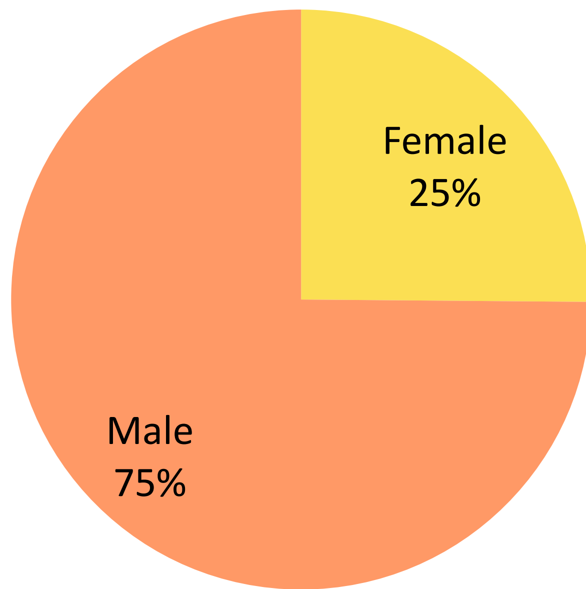
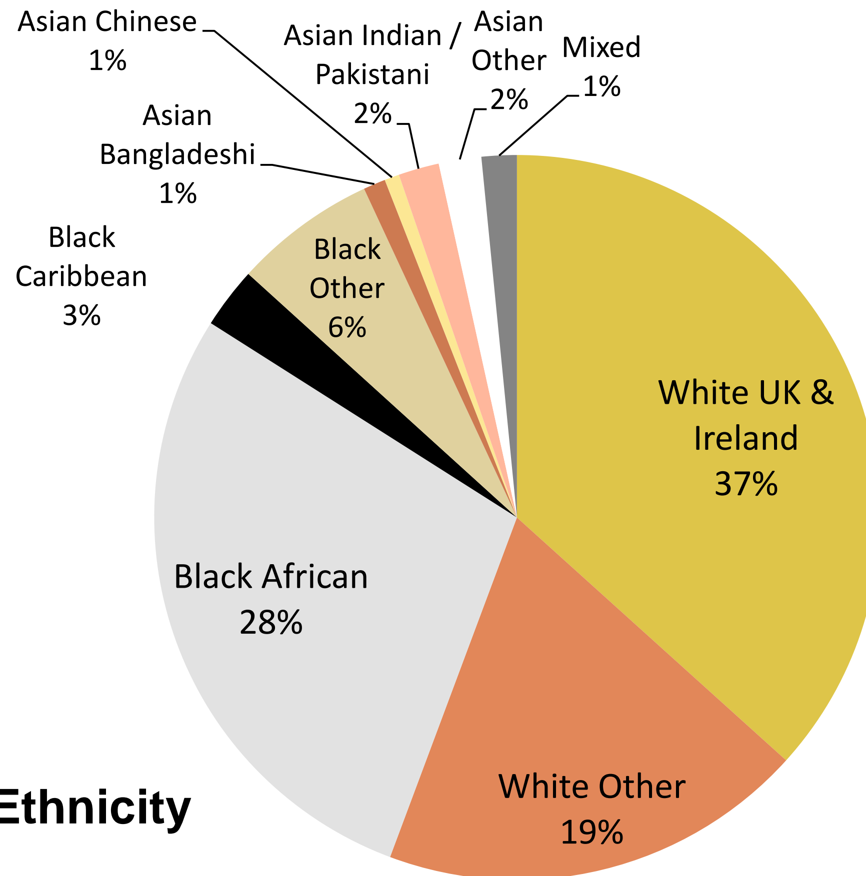
Grahame Hayton Unit – HIV outpatients

Gender





Ethnicity

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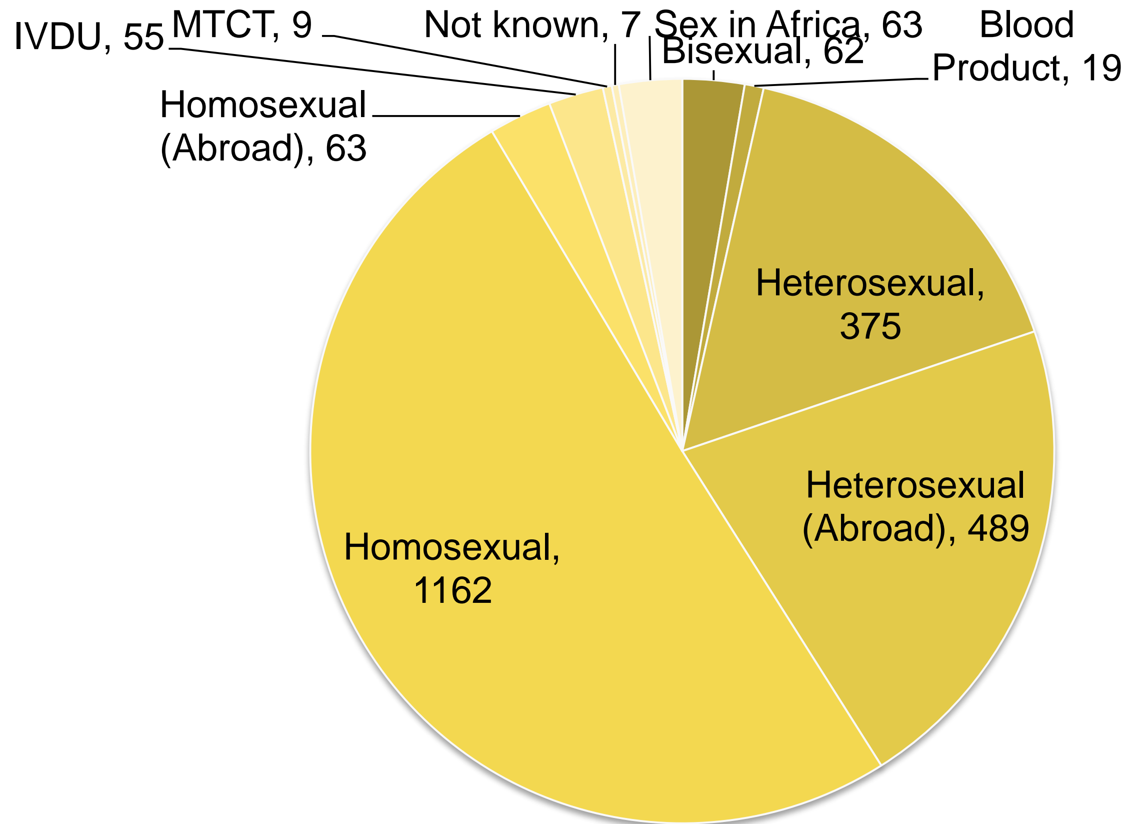
Grahame Hayton Unit – HIV outpatients: risk factors



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Graham Hayton Unit interdisciplinary team

- Medical staff
- Psychology
- Neuropsychology
- Consultant / advanced practitioner nursing
- Clinical Nurse Specialists
- Health advisors
- Specialist Pharmacy
- Specialist Social work
- Specialist OT*
- Specialist PT*
- Specialist Dietetics*

Grahame Hayton Unit structure

- HIV Consultant doctors have sub-specialty clinics, including:
  1. HIV & oncology
  2. HIV / hepatitis
  3. Lost to Follow-Up clinic
  4. HIV neuro/rehabilitation clinic – input from HIV doctor, neurology registrar, OT and PT
  5. HIV and older people's clinic – input from HIV doctor and geriatrician – OT input trialled but few referrals

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GHU Occupational Therapy and Physiotherapy

- Referral sources: primarily clinic doctors, also clinic nursing staff, psychology, dietitians
- Referral reasons: Varied, must be HIV related
- Assessment: In the HIV clinic or within the rehabilitation services (gym, ADL suite) as indicated
- Interventions: Individual treatment sessions, signposting to other services, group programme (SMARTgroup)
- Currently undergoing redesign due to service changes

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GHU 1:1 clinic examples of range of diagnoses

HIVE, old PML, movement disorder	KS, COPD, frail, alcohol misuse	Ca prostate, falls, SDH, cognitive issues	HIVE
toxo, paranoid shizophrenia	flare-up of extapyramidal symptoms (previous toxo), lipo	spasticity and retrobulbar neuritis, isolated	post Burkitts neuropathy, LBP, frail
HIVE 2011, ataxia, blind	Marked fatigue knee pain, poor sleep, peripheral neuropathy, poor attender	Severe PML, improving, wants to live independently	Hep B, cancer, not coping at home

GHU 1:1 clinic examples of range of assessments

- PRPP
- Functional assessment
- Home assessment
- Upper limb assessment
- Visual screen
- SARA
- Self rating fatigue scales
- ACE-III

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GHU 1:1 clinic examples of interventions

- Fatigue management, sleep hygeine
- Return to work advice / interventions
- Manual therapies / practice (often joint with PT)
- Home exercise programme – upper limb
- ADL practice in OT dept
- Splinting and orthoses
- Referral to voluntary sector
- Referral for community rehabilitation
- Referral to psychology / SW / CNS
- Referral to neuropsychology
- Equipment or adaptations
- SMARTgroup

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SMARTgroup: initial set up (2005)

Outpatients

- with HIV related impairments / disabilities
- who needed a more intensive rehab programme than individual outpatient attendance
- aren't appropriate for a programme elsewhere

Recently discharged patients

- who needed a short period of top-up rehabilitation
- not available elsewhere
- typically working age patients post respiratory / systemic illness

Inpatients

- who could manage gym attendance
- who were already known to the inpatient team
- require rehabilitation or maintenance

SMARTgroup

- Programmes individualised to goals, with some individual and some group activity
- Assessments and interventions used evolved over time
- Also an opportunity for peer support and socialisation

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SMARTgroup: Assessment completed pre/post

Strength

- One rep max

Endurance

- Six minute walk test

Flexibility

- Sit-and-reach

Anthropometry

- weight, height, mid-upper arm, bio-impedence

Functional

- initially trialled FIM/FAM and FAHI
- later changed to in-house functional screen and in house ten point VAS symptom rating scale

Goal setting

- in house four point goal setting (achieved, partly achieved, not achieved, not relevant)

Other measures as indicated

- e.g. Berg Balance, Jebsen-Taylor Hand Function Assessment, Perceive Recall Plan Perform

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SMARTgroup symptom self rating scale

- Rating, on 1-10 (never – rarely – occasionally, sometimes – frequently – all the time)

I feel tired	I feel weak	I have difficulty concentrating
I have difficulty remembering things	I have difficulty walking long distances	I have problems with coordination
I have pain	I have difficulty sleeping	I have poor appetite

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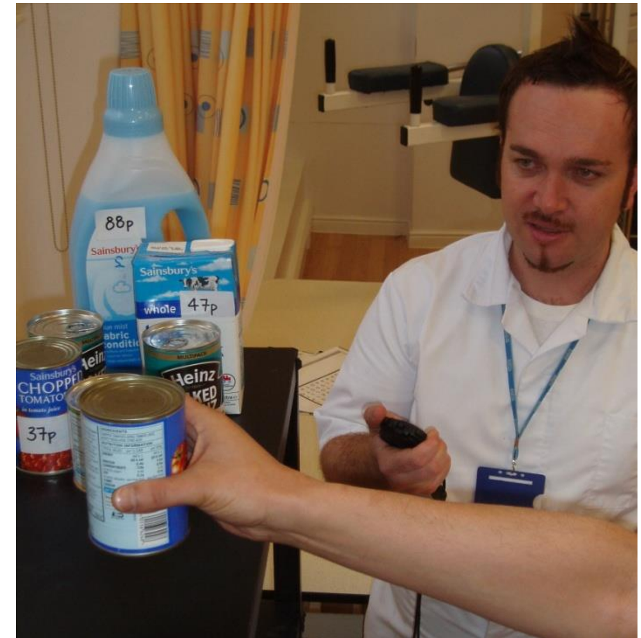
SMARTgroup: Example programme

- Warm ups
- Cardiovascular (bike, treadmill)
- Resistance (multi-gym)
- Individualised programmes
  1. Hand function – strength, coordination
  2. Attention, recall, processing
  3. Balance, coordination (Wii fit)
  4. Functional (simulated shopping tasks)
- Education: fatigue management, diet, stress management
- Relaxation therapy, warm-down, stretches



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SMARTgroup: analysis

- Inclusion criteria:
  1. only patients who attended as an outpatient
- Methodology
  - Random selection of 70 sets of attendance data
  - Review of notes and coding for
    - primary diagnosis
    - primary presenting complaints
    - goal areas
    - completion and reasons for non-completion
    - barriers to attendance

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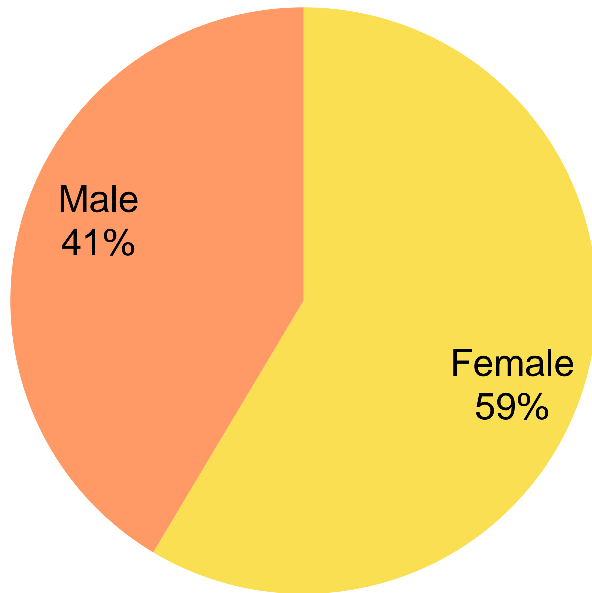
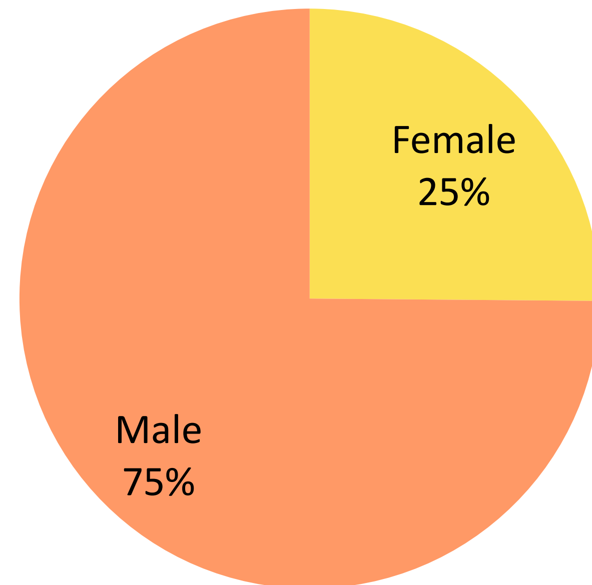
SMARTgroup: Gender





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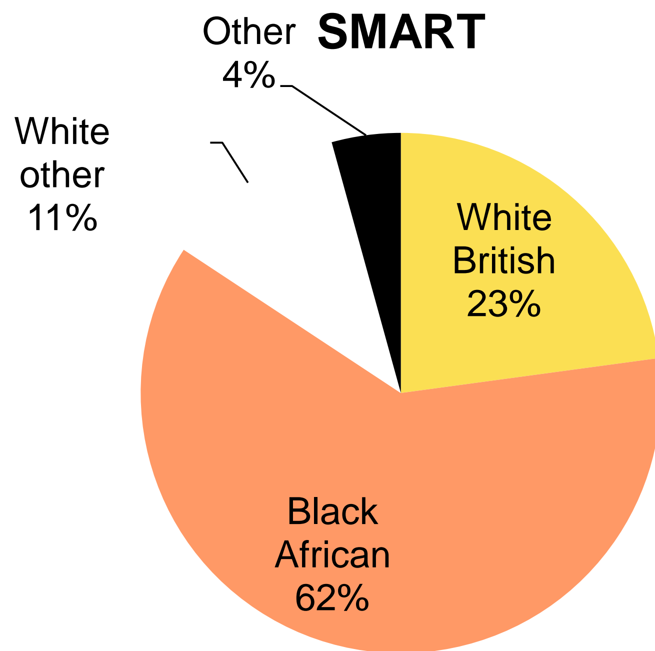
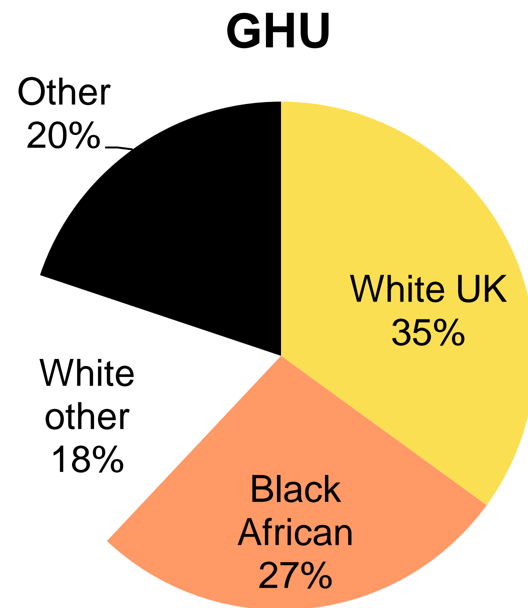
SMARTgroup: Ethnicity





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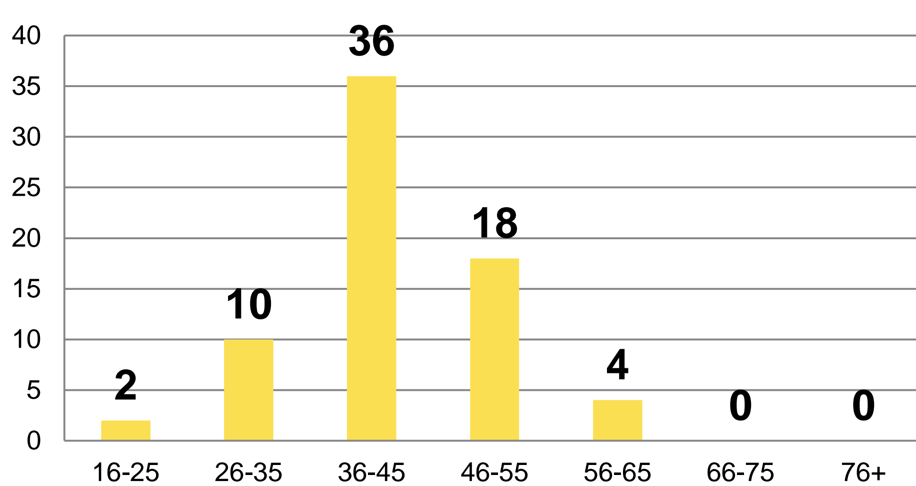
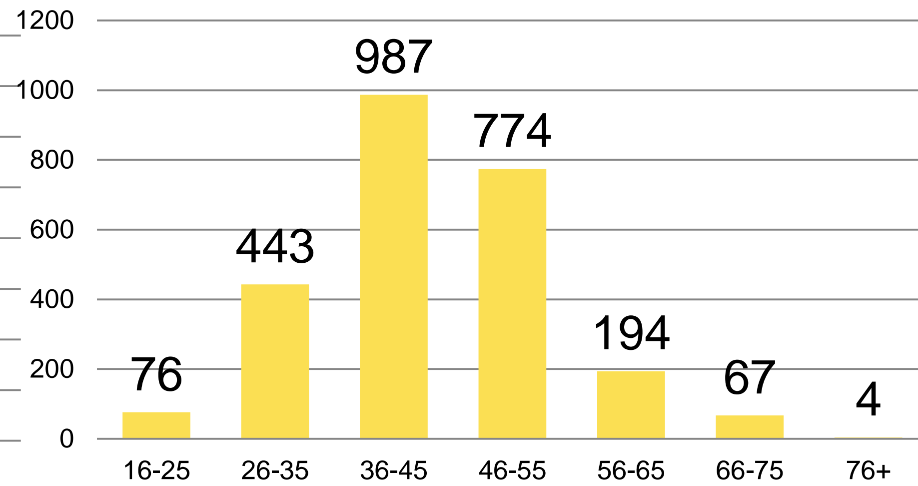
SMARTgroup: Age





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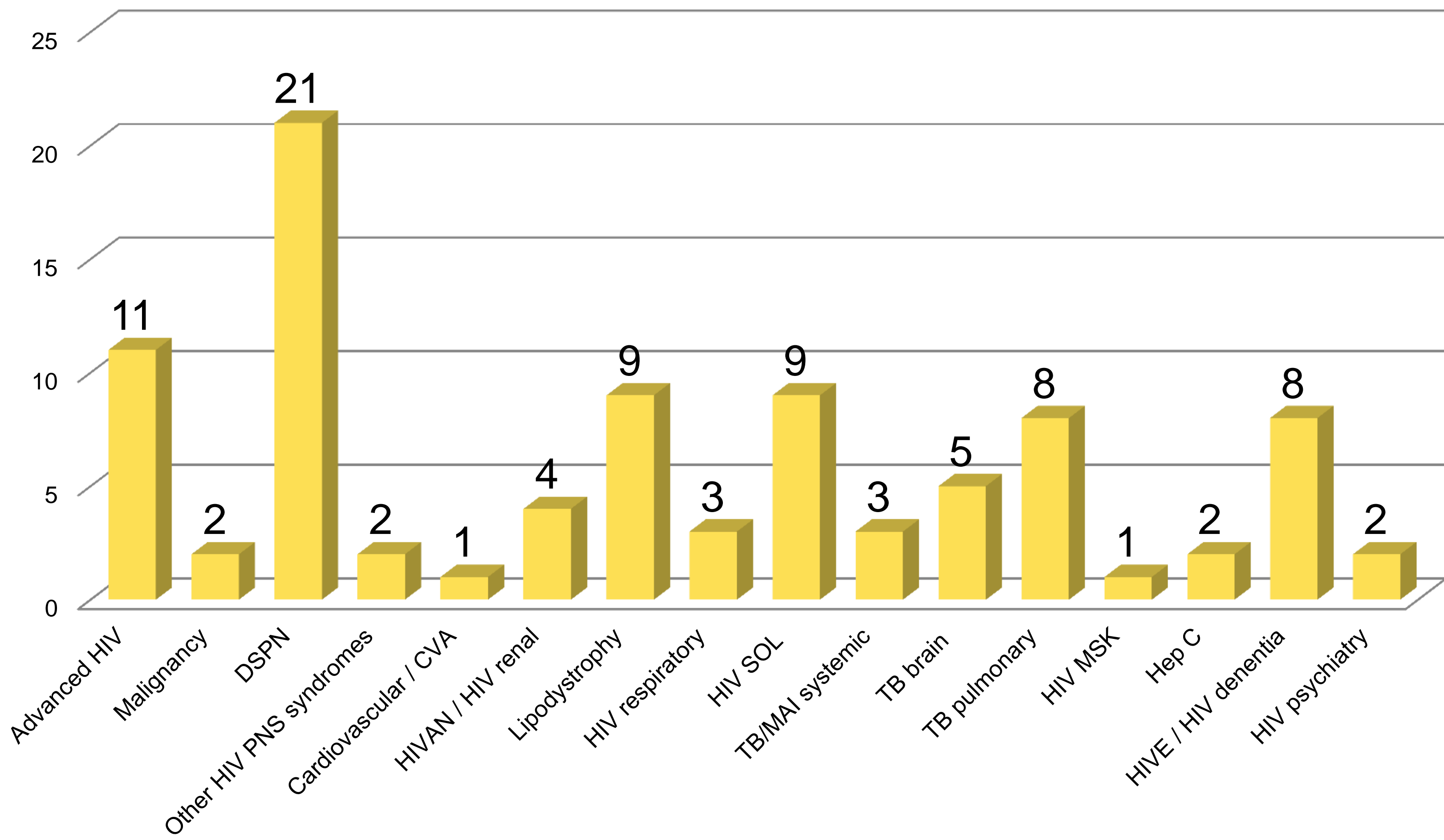
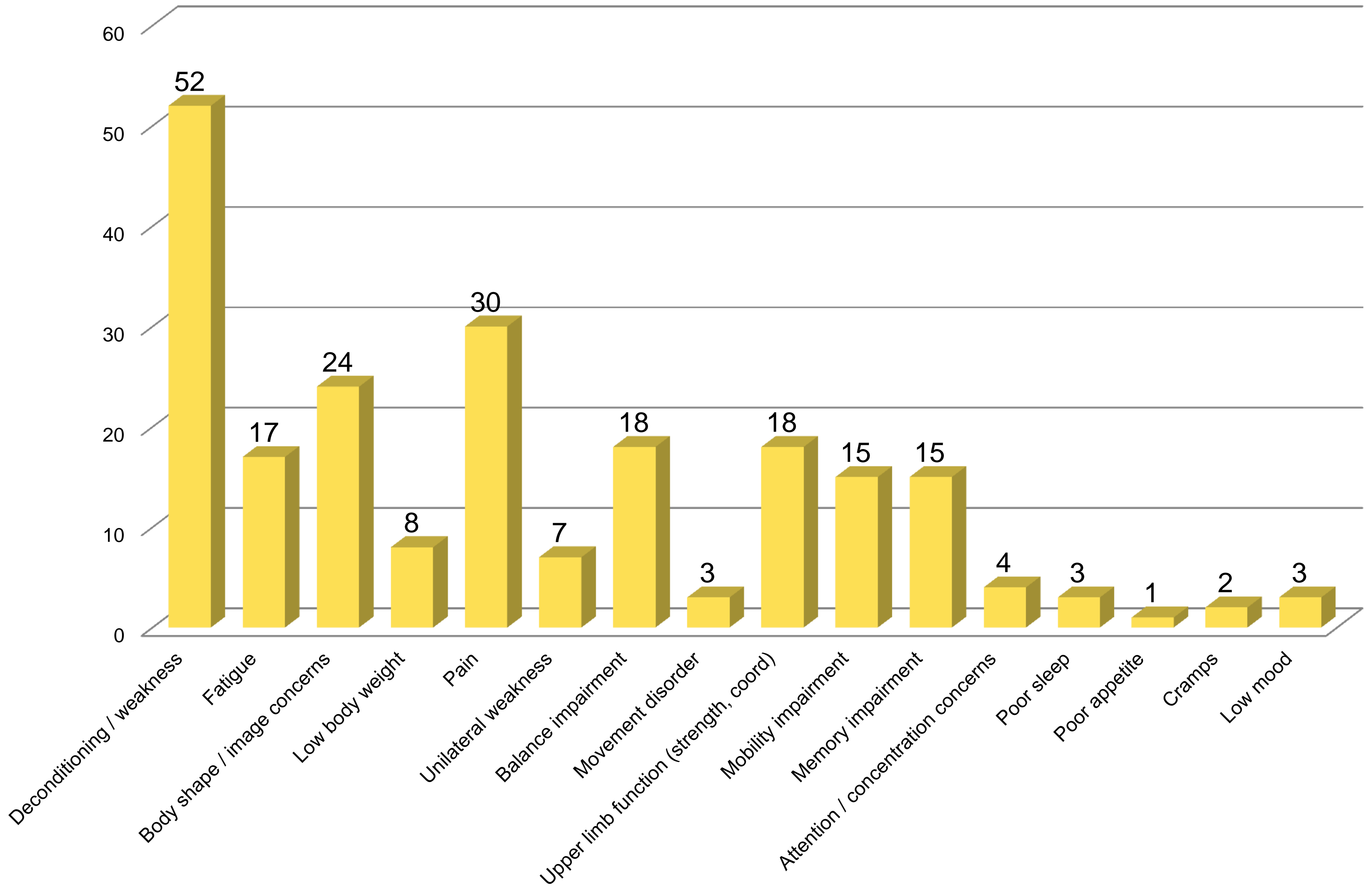
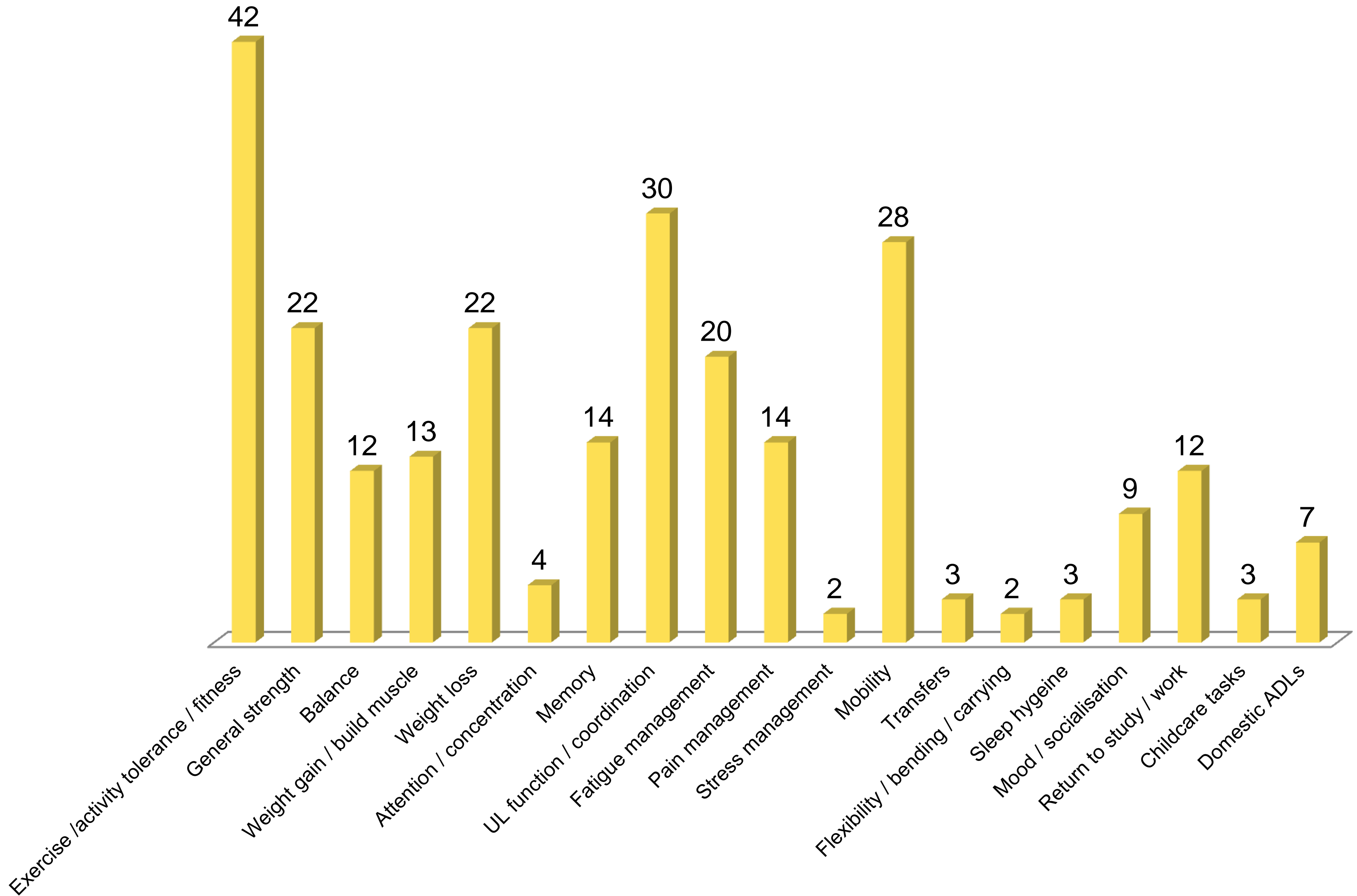
SMARTgroup

Primary HIV related diagnosis




SMARTgroup presenting complaints
60
50
40
30
20
10
0
52
17
24
8
30
7
18
3
18
15
15
4
3
1
2
3
Deconditioning / weakness
Fatigue
Body shape / image concerns
Low body weight
Pain
Unilateral weakness
Balance impairment
Movement disorder
Upper limb function (strength, coord)
Mobility impairment
Memory impairment
Attention / concentration concerns
Poor sleep
Poor appetite
Cramps
Low mood


SMART group Goal areas
42
22
12
13
22
4
14
30
20
14
2
28
3
2
3
9
12
3
7
Exercise /activity tolerance / fitness
General strength
Balance
Weight gain / build muscle
Weight loss
Attention / concentration
Memory
UL function / coordination
Fatigue management
Pain management
Stress management
Mobility
Transfers
Flexibility / bending / carrying
Sleep hygeine
Mood / socialisation
Return to study / work
Childcare tasks
Domestic ADLs

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SMARTgroup

Completion

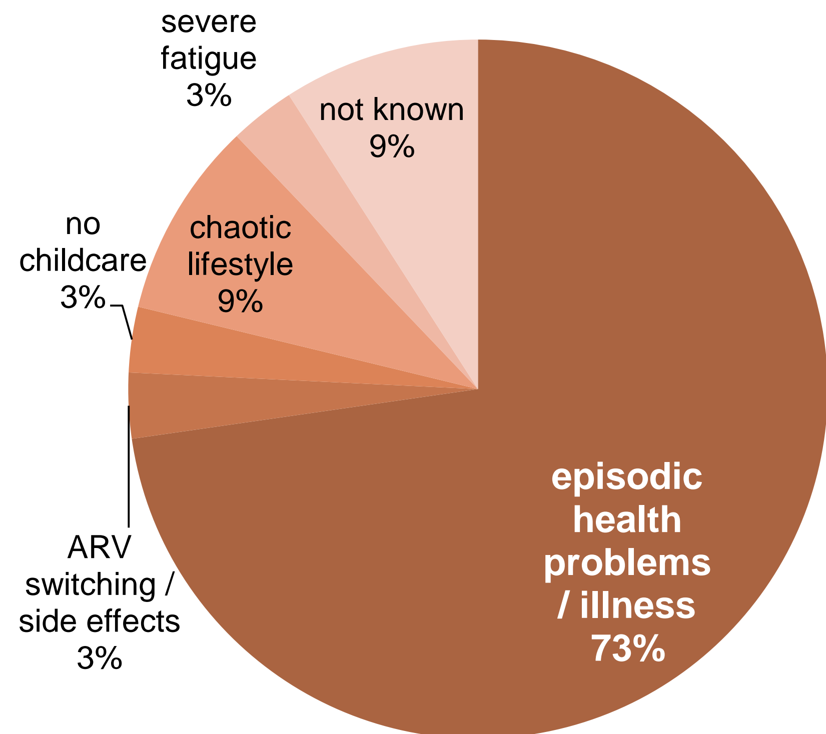
1. Programmes completed 37
2. Programme discontinued 33

Completed programmes

1. Mean number of sessions 16.7 (range 5-41)

Uncompleted programmes

- Mean number of sessions 6.5 (range 1-17)



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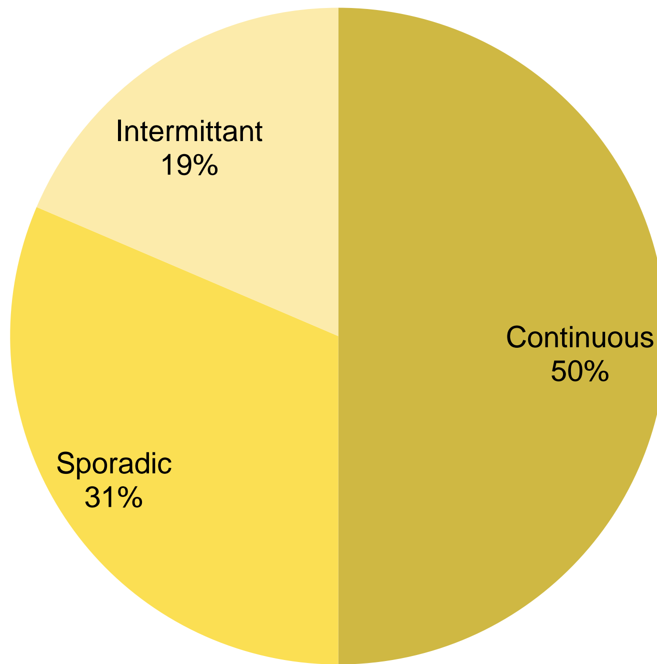
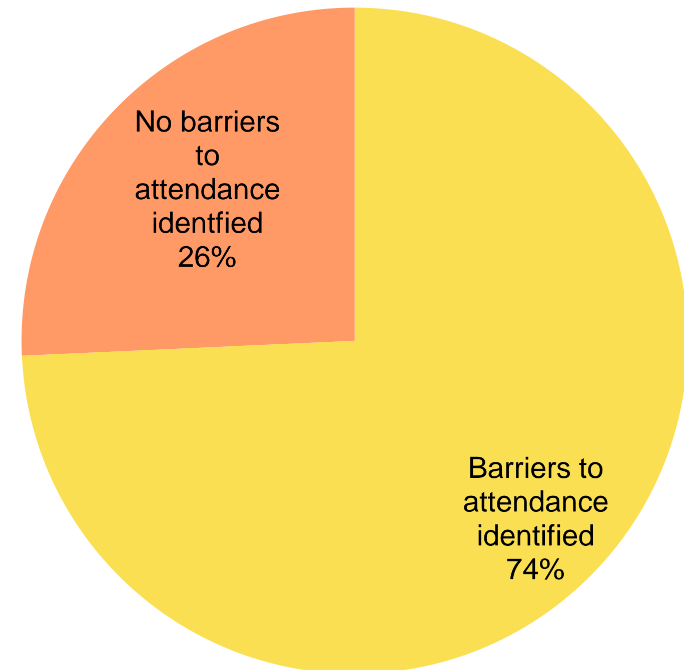
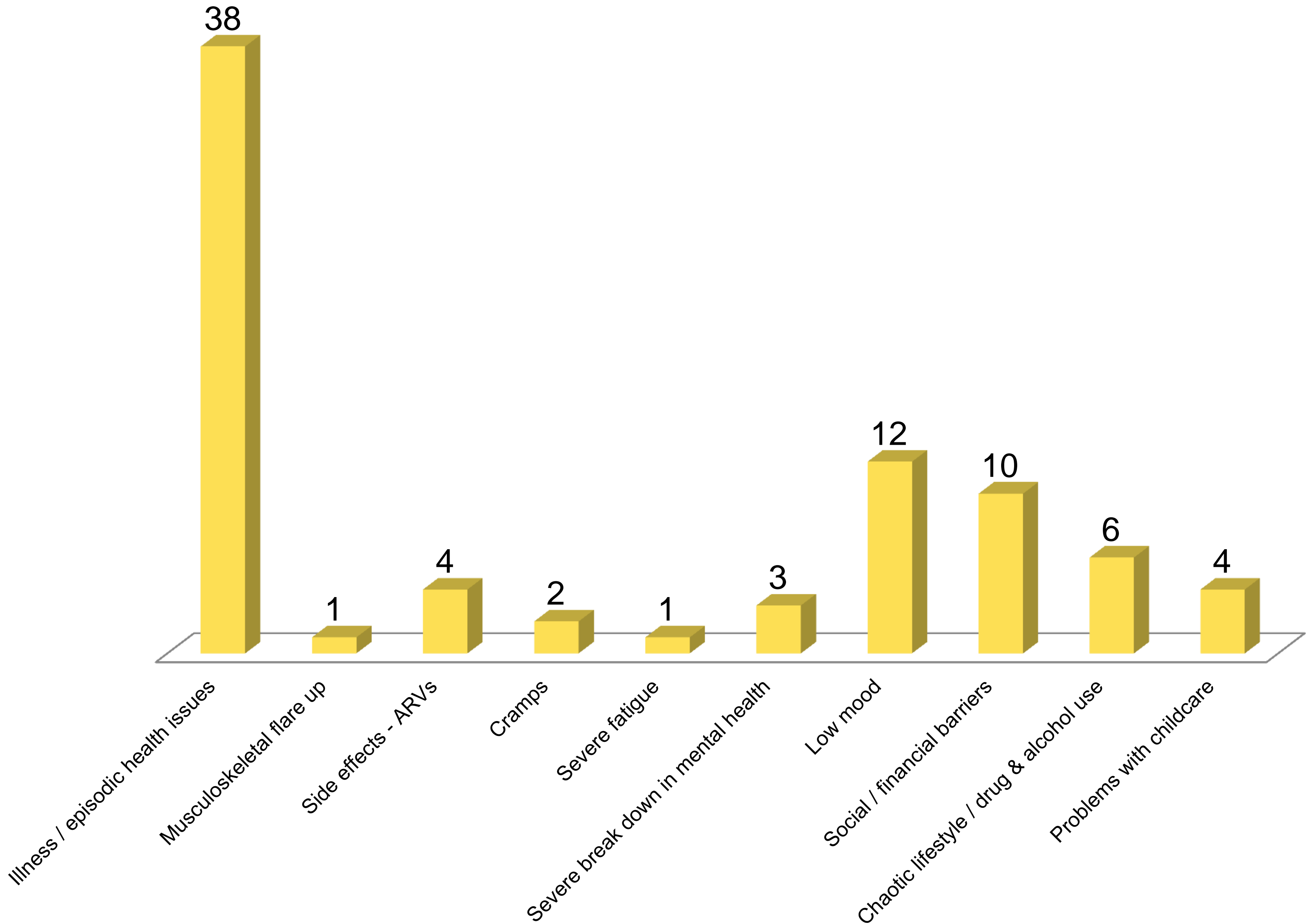
SMARTgroup

Pattern of attendance



Barriers to attendance




Barriers to attendance
38
1
4
2
1
3
12
10
6
4
Illness / episodic health issues
Musculoskeletal flare up
Side effects - ARVs
Cramps
Severe fatigue
Severe break down in mental health
Low mood
Social / financial barriers
Chaotic lifestyle / drug & alcohol use
Problems with childcare

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SMARTgroup: subjective observations and patient feedback

- Patients developed relationships quickly that spanned outside the group, that crossed ethnicity / gender / age
- More experienced patients took up a mentoring role, particularly with inpatients
  1. especially if newly diagnosed or experiencing first catastrophic health issue
- Relationships continued post-group as patients "graduated" to other programmes
- Participants frequently reported they valued and enjoyed the group

SMARTgroup: summary of initial analysis

- Compared with the clinic population there is an over-representation of women and non-white British populations
- Episodic health problems are highly prevalent in this population
- Mood and social/financial barriers to attendance also impact successful attendance

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SMARTgroup: implications

- Need to design flexibility in to programmes to be effective and responsive to
  1. Episodic health
  2. Social, cultural and financial needs
- Current tools have limitations, don't capture episodic nature of HIV
- Most effective goals are real-life, achievable, meaningful goals; appears key in achieving programme completion

SMARTgroup analysis - planned

- Stage II of analysis
  1. Outcome data – what happened to patients after completion
  2. Analysis of goal attainment data
  3. Analysis of impairment level change data (anthropometry, flexibility, mobility)
  4. Analysis of goal setting quality with completion data
  5. Analysis of impairment testing versus goal data