

## Nothing About Us, Without Us: Co-Designing with Caregivers

Presenters: Uzma Aziz Irfan, Kendelle LaBella and Nena Pendevska

#### Overview

- Ontario Health Teams
- Approach to engagement of caregivers
- Caregiver Advisory Group
- Co-designing with caregivers
  - NICE fund
  - Caregiver Support Initiative
  - Caregiver Navigation Support
- Question & Answer



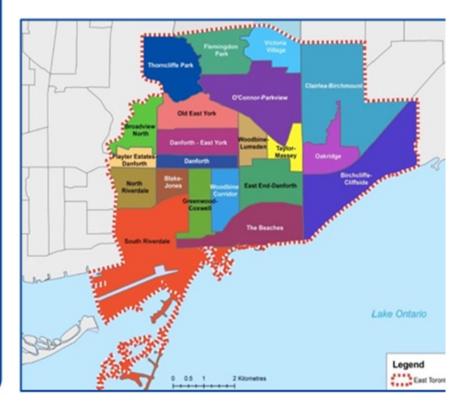


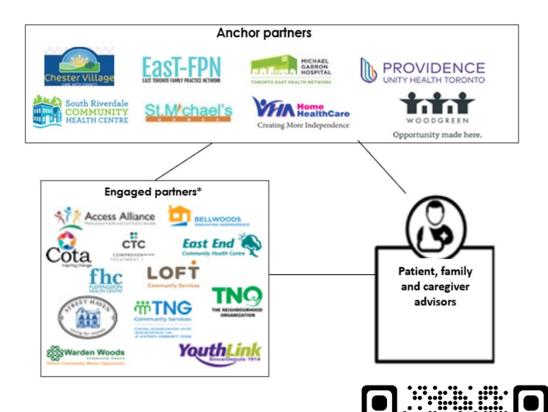
#### East Toronto Health Partners

# We serve 350,000+ people who five in East Toronto and who choose to receive care here Child/Youth (age 0-19): 23.1% Seniors (ages 65+): 13.7% Seniors Iving alone: 32% 21 Diverse Neighbourhoods 50+ languages spoken 5 Designated Neighbourhood Improvement Areas: Thorncliffe Park Victoria Village Oakridge

Flemingdon Park Taylor-Massey

### **East Toronto:** Who we serve

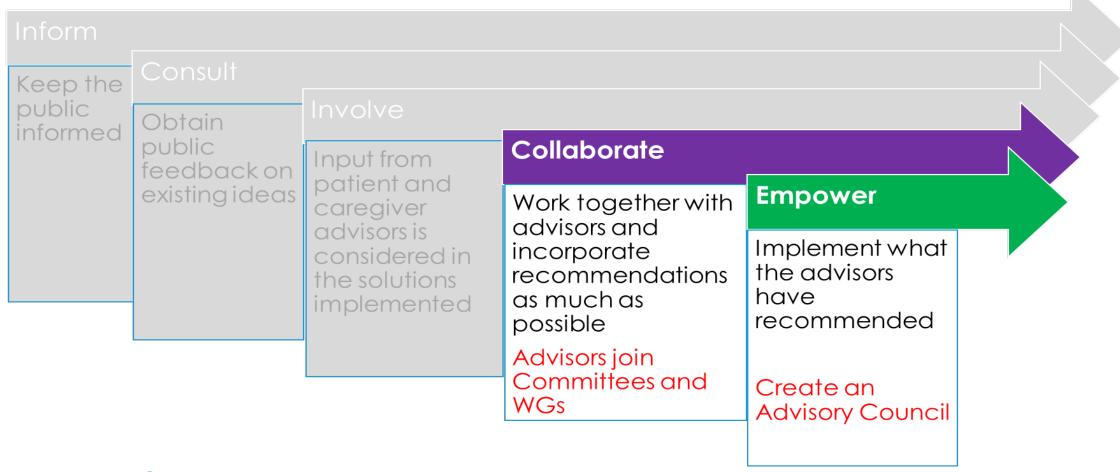








#### Working at the far end of the engagement spectrum







#### What does success look like?



What did the patient and caregiver advisors say?

Increased community-led initiatives &

community co-production

to improve health and well-being, enhance patient/caregiver experience, improve equity

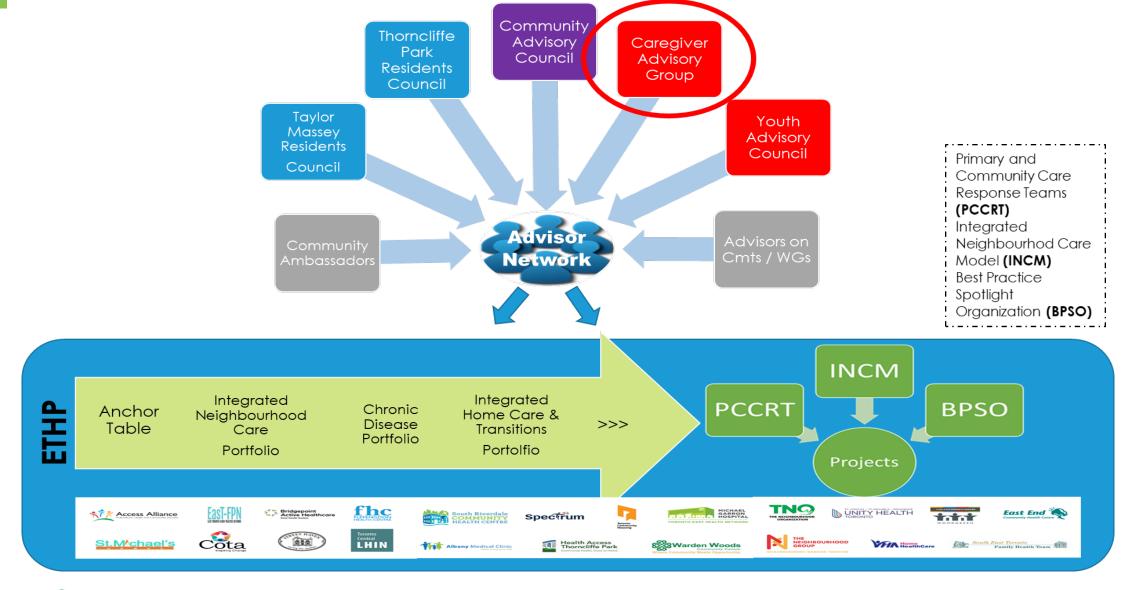
Councils need certain resources such as funds, staff, patients, caregivers, residents

In order to participate in codesign

In order to achieve certain goals (have impact)











#### Caregiver Advisory Group



Aspa Cindy Hannah Jill Khadija Michelle Monica Pat **Patty Purnima** Sandra Sarah Sheri Uzma

- 14 caregivers
- Diverse representation
- Monthly and ad-hock meetings
- Hands-on participation
- Focus on developing supports for caregivers in East Toronto and reaching those from Ethno-Cultural and Diverse Communities





#### Impact of caregiver engagement at ETHP

- Context matters: East Toronto
- Caregiver supports based on caregiver needs in East Toronto Reduce caregiver stress and burnout Promote the role of caregivers in the healthcare system Culturally appropriate/ Language specific resources Navigation support
- ETHP Programs and services responsive to caregiver needs
   Support caregivers to provide care to care recipients at home
   Improved transitions
   Support hospital discharge / Reduce ALC
   Reduce ER visits





#### Caregiver NICE fund (2020)

- Help reduce caregiver stress and burnout during Seasonal Surge (November – March) for caregivers in the area served by Michael Garron Hospital and ETHP
- Support people on low income (either the caregiver and/or the care recipient)
- Basic necessities: meals on wheels, clothing, medication, continence supplies, beds, phones/ tablets, glasses, mobility aids
- Services: extreme cleaning, decluttering, moving, pest control, caregiver respite, transportation, falls prevention





#### Caregiver Support Initiative (2021)

#### Tear-pads for Dr's offices and pharmacies:



#### Fridge magnets:



#### Subway posters:



#### Webpage:



#### East Toronto Health Partners

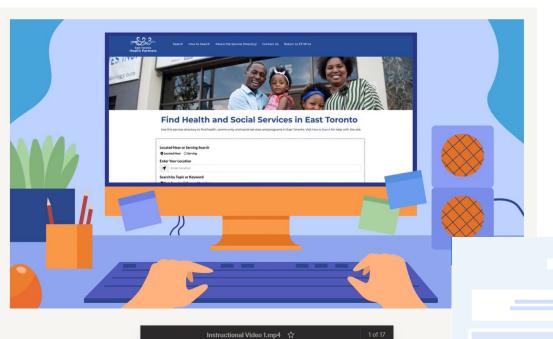
#### OMNITV ads:



#### Posters:



#### Caregiver Navigation Support (2022)







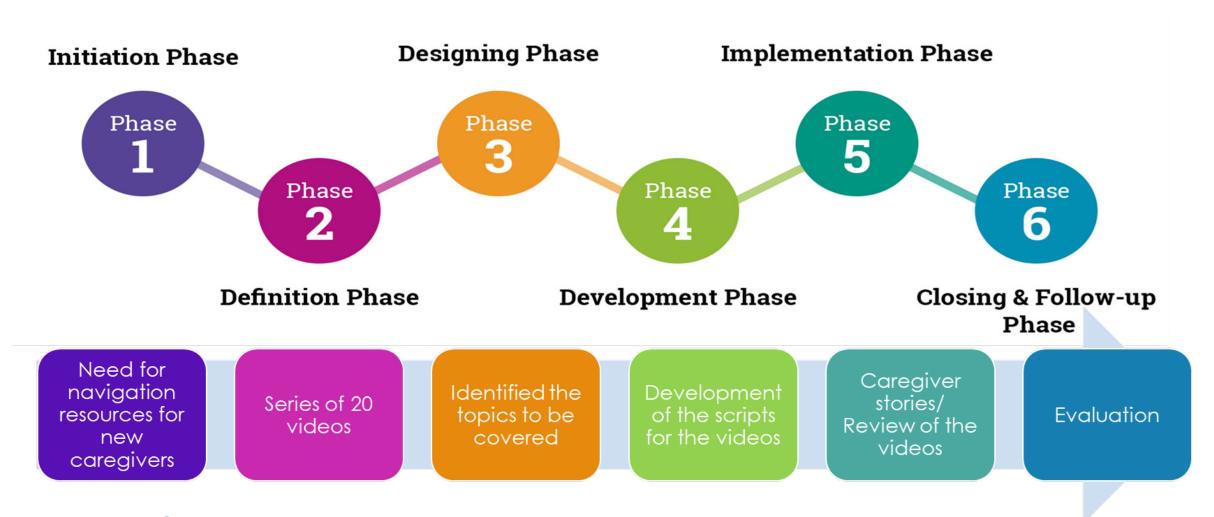








#### The co-design process







#### What is important to our caregivers

- True co-design process and early involvement
- Addressing concerns and challenges for caregivers in East TO
- Tangible results developing resources based on caregiver needs
- Culturally appropriate outreach/promotion
- Accessibility
  - Languages: Urdu, Bengali, Greek, Cantonese, Mandarin, Farsi, Gujarati, Tamil
  - Formats: Print, Digital, Phone/ Live person
- Prioritizing feedback from the caregiver group vs organizational practices





#### Meaningful and empowering methods to engage caregivers

- Leveraging their individual strengths
- Recognition of their participation/ expertise (e.g. honorariums)
- Learning opportunities
- Commitment to valuing their time and input
- Accommodation (e.g. meeting schedule) and accessibility (e.g. online mtgs / calling in)
- Addressing power differentials within the group / valuing and acknowledging everyone's perspective
- Sense of ownership





#### We want to learn from you

- How are you currently engaging caregivers?
- Where are you on the engagement spectrum (Inform, Consult, Involve, Collaborate, Empower)?
- What challenges are you experiencing?
- How do we fund and support initiatives that the caregivers prioritize and bring forward?

